



NEW JERSEY

Caregiver Task Force Report

2022



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Message from the Chair

Greetings. I write today on a topic of great importance: the well-being of the over one million New Jerseyans who are caregivers and those who are cared for by them. The Legislature created the Caregiver Task Force to research the issues, determine the availability of caregiver support services in the State, and provide recommendations for the improvement and expansion of such services. The members of the Task Force are pleased to submit the following report to the Legislature and Office of the Governor. While we began our work in the midst of these precarious times, the COVID-19 pandemic exposed and exacerbated several pre-existing weaknesses within our caregiving system. Our recommendations are based on nationally available information, our members' personal and professional experiences, and firsthand experiences shared by others at the three public testimony listening sessions we held throughout 2021.

The members of this Task Force represent and support caregivers and care recipients across their lifespans, many as caregivers themselves. Their concerns include those of caregivers of older adults as well as individuals across all stages of life, some of whom live with mental illness, intellectual or developmental disabilities, and/or physical disabilities.

In order to effectively complete the task assigned, the Task Force first needed to identify and compile an inventory of the state policies, resources, and programs currently made available to support or assist caregivers. We then solicited and received testimony from caregivers of all kinds and from all walks of life across the State. A survey was also created and disseminated through various networks. The overwhelming response we received showed us yet again how many lives are touched by caregivers and how important our mission is.

Several important themes emerged, and numerous recommendations have been suggested. We recommend creating a public awareness campaign to more clearly define what a caregiver is; the campaign should also include an educational component to describe how caregivers can be supported.

The creation and development of a Caregiver Hub within the Department of Human Services is of utmost importance to prevent programs or policies from overlapping, conflicting each other, or creating gaps in the system. The State can also facilitate a dedicated "network of connectivity" among various departments and stakeholders to facilitate access to services.

Caring for someone who is sick, elderly, or has a disability, whether at home or in an institutional setting, is extremely costly. We urge you to review and act on the many recommendations we have presented for financial relief and funding that support caregiver services. In order for these recommendations to reach everyone they can, however, a concerted effort to improve caregiver self-identification must also be pursued.

Finally, while this Task Force is focused on unpaid caregivers, the significance of the paid caregiver workforce crisis cannot be ignored. As the president & CEO of the Home Care & Hospice Association of New Jersey, I know firsthand how providers of all sizes and types struggle mightily to recruit and retain quality staff to take care of their patients. More work needs to be done across the board to ensure that if someone wants to be cared for in the comfort of their home, there will be a caregiver—whether they be paid or unpaid—to care for them.

While the Task Force has completed its objective of providing its recommendations to the Legislature, community input on caregiver needs should not end. The spirit that embodies the work of the Task Force must continue through the implementation of the following recommendations.

Lastly, I would be remiss if I did not commend the wonderful staff charged with working alongside the Task Force. This undertaking could not have been accomplished without the care, dedication,

and commitment shown by the Department of Human Services' Division of Aging Services staff. Their dedication to the mission of helping people in need made this report possible.

Respectfully submitted,

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Executive Summary

New Jersey Public Law 2018, Chapter 166, called for the formation of the governor-appointed New Jersey Caregiver Task Force. The Task Force was commissioned to compile an inventory of all state policies, resources, and programs currently available to support or assist caregivers, as well as to identify and survey New Jersey family caregivers to assess their current circumstances, experiences and expressed met and unmet needs. In addition, P.L.2018. c.166 called for the compilation and presentation of a report that summarizes the Task Force's findings and outlined prioritized recommendations to support unmet needs.

The Task Force met from March 2020 through March 2022. During the convening, the Task Force surveyed New Jersey family caregivers, held three family caregiver testimonial sessions, and reviewed current state data and resources. Throughout the duration of the Task Force, some specific themes repeatedly arose. These themes are as follows:

- There is a lack of awareness and understanding among caregivers of the current resources available to caregivers in New Jersey;
- Caregivers face difficulties in accessing the resources that currently exist;
- Caregivers face challenges in navigating the path to obtaining existing support and services, including understanding the eligibility requirements;
- There is a lack of available, skilled staff to assist caregivers with their needs; and
- There are specific geographic areas within New Jersey where caregiver services are not adequately available.

Although there are numerous similarities among different types of caregivers, this Task Force found that looking at caregivers as one category can be misleading. Caregivers have differing needs dependent on the needs and wishes of the care recipient, the circumstances of the caregiving situation, and the needs and wishes of the caregiver. Throughout this report, the Task Force attempts to honor those unique needs while also honoring the similarities found among all caregivers.

Many caregivers report that they feel isolated and overwhelmed, and that they often experience frustration and grief while facing the challenges of caregiving on their own. They express that caregiving has had a significant negative impact on their finances and has severely limited time for their own self-care. In addition, caregivers expressed the need for more expansive and easily accessible respite services. Although some caregiver resources are available online and throughout the State of New Jersey, caregivers are often unaware of them; services are reportedly said to be difficult to find, identify, access, and navigate.

Searching for appropriate resources should not be another burdensome item added to the long list of responsibilities of a caregiver. Caregivers spend an inordinate amount of time and money seeking resources and providing care, which leaves little to no time left for embracing healthy lifestyle habits that reduce chronic disease risk factors and boost overall quality of life. This is particularly important for caregivers, who are at a higher risk for poorer health outcomes and lower perceived quality of life.

Family caregivers provide an essential service that ultimately saves the State money by keeping care recipients cared for in their homes. The Task Force feels it is imperative that New Jersey's family caregivers are supported with resources that are convenient, easy to understand, and available to caregivers at times and in places they can readily access. This report identifies and addresses the challenges of raising awareness of available services, facilitating access to those

services, and expanding caregiver services where the need has been expressed by family caregivers.

As such, the Task Force shares its findings and recommendations outlined in this report for exploration, discussion and consideration. Swift movement toward these recommendations is critical, especially in the priority areas listed above. The implementation of these recommendations will be ongoing, and it must be done in coordination with family caregivers, care recipients and other key stakeholders.

Key Report Terminology

Caregiver or Family Caregiver: An individual who has a significant personal relationship with, and who provides assistance to, a care recipient with a chronic or other health condition, disability, or functional limitation. These individuals are primarily unpaid, although there are unique situations in which a family caregiver is paid for a portion of the services provided. This role is typically voluntary for the majority of the care. This term includes immediate and extended family members, such as parents, spouses, grandparents, siblings, partners, friends, and children who care for family members, regardless of the type of assistance needed. This term also includes people who provide care on both a part-time and full-time basis.

Paid Care Staff: An individual who is paid to serve in the professional role of providing assistance to an individual with a chronic or other health condition, disability, or functional limitation. This term is meant to encompass many types of caregivers, including Home Health Aides (HHA), Personal Care Assistants (PCA), Certified Nursing Assistants (CNA), Registered Nurses, Homemakers, Direct Support Professionals (DSP), Doctors, and others.

Volunteer Care Staff: A trained, unpaid individual who voluntarily serves in the role of providing assistance to an individual with a chronic or other health condition, disability, or functional limitation.

Care Recipient: An individual with a chronic or other health condition, disability, or functional limitation who is receiving assistance.

Caregiving: Impact & Trends

What is caregiving?

Caregiving is an essential role that is woven into the fabric of just about every culture and society. Most of us are, have been, or will be a family caregiver, or will need the help of a caregiver to live independently. Caregivers are the first line of assistance for most individuals needing care, helping older adults and people with health conditions, disabilities, or functional limitations to remain at home and out of costly, taxpayer-funded institutions like nursing homes. Caregivers provide support in many ways, ranging from assistance with activities of daily living, grocery shopping, or paying bills to attending medical appointments and managing medications. Caregivers are often responsible for needs beyond typical day-to-day care, particularly the emotional and social needs of care recipients. Caregivers may also perform complex medical tasks, such as giving injections or treating wounds. For these reasons and more, unpaid family caregivers are the bedrock of our Long-Term Services and Supports System (LTSS).

A recent study by the Home Alone Alliance, an AARP-led collaborative, found today's caregivers are increasingly providing care they call "intense and complex". This type of care includes performing medical/nursing tasks and managing multiple health conditions that are often accompanied by pain. These caregivers often carry a heavier responsibility than those who do not perform these tasks, spending more than twice as many hours per week providing care than caregivers who do not perform medical or nursing tasks.¹ Similarly, a 2020 report on caregiving in the U.S. by the National Alliance for Caregiving and AARP also found that half of caregivers surveyed are performing medical/nursing tasks for individuals with challenges in physical, cognitive, and behavioral health. Caregivers that perform medical/nursing tasks are also twice as likely to be helping with activities of daily living, such as bathing, dressing, and toileting.²

"It is critically important to recognize the bulk of those giving care, referred to as informal caregivers, are family members, relatives, spouses, partners, neighbors both young and old. The "job" of caregiving varies depending upon the condition of the care receiver ranging from acute situations where recovery can be short-term to that of a lifetime of caring for a child with special needs, or the long-term commitment in caring for a person with cognitive impairment/dementia."

– Testimony from New Jersey Area Agency on Aging Association

Non-medical care can be just as crucial to ensuring that care recipients remain at home. The Task Force has found that over 80 percent of caregivers assist with shopping, transportation, food preparation, household chores, and housekeeping, often in conjunction with assisting with care coordination and medical/nursing care. Helping care recipients remain in community-based settings rather than traditional residential care settings is made more difficult when not enough home- and community-based services and supports are in place. This puts additional pressure on families and caregivers who want to honor and support their care recipient's wishes to remain at home but need to fill the gaps in long-term services and supports. Caregivers increasingly provide and monitor complex care at home by navigating the care system, advocating for their care recipient, and paying for services to help the person with care needs.

Caregivers also help their care recipients navigate LTSS when they need additional supports or care. The healthcare and LTSS systems in the United States, including in New Jersey, are often decentralized, with many different places to go for care, services or supports. Navigating this fractured system is often described as frustrating, stressful, and costly. Caregivers, and not just their care recipients, are greatly impacted by the choice of where to go for care and the implication it has for costs. More caregivers say it is difficult to coordinate their recipient's care across various

providers, increasing from 19 percent in 2015 to 26 percent in 2020. About one in four caregivers (27 percent) report it is difficult to find affordable services in their recipient's area.³

Who are family caregivers?

In New Jersey, there are over one million unpaid family caregivers who make it possible for their care recipients to live independently at home.⁴ Like New Jersey, caregivers are diverse, cutting across all generations, racial/ethnic groups, incomes, educational levels, family types, gender identities, and sexual orientations.⁵ Unfortunately, accurate statistics about the varying types of caregivers are difficult to come by. As statistics about caregivers of children with disabilities, individuals with mental illness, and individuals with intellectual or developmental disabilities may not be accurately included in these numbers, these totals may be undercounted.

More than one in five Americans (21.3 percent) are caregivers. This totals an estimated fifty-three million adults in the United States, up significantly from the estimated forty-three-and-a-half million caregivers (18.2 percent) in 2015.⁶

Nationally, the average age of a caregiver is 49, and six in ten caregivers report that they are working while caregiving.^{7,8} On average, caregivers work 35 hours per week but spend an additional 23.7 hours per week, on average, providing care. The split between ages of caregivers is fairly even, with 46 percent between 18 and 49 years of age and 54 percent aged 50 and over.⁹

Caregiving is a cross-generational issue, and different age cohorts face distinct challenges. Millennial and Generation X caregivers are more likely to be employed while caregiving than their Baby Boomer or older counterparts, but older generations of caregivers typically spend more time caregiving on a weekly basis.¹⁰ Youth caregivers under the age of 18, a surprisingly large group estimated at over five million in number, often have their education impacted through missing assignments or class time.¹¹ They are also at a higher risk for negative health, educational, and social outcomes than their peers.¹²

Caregiving is also an issue that spans demographic categories. Three in five caregivers are women (61 percent) and two in five are men (39 percent). Sixty-one percent of caregivers report being non-Hispanic White, 17 percent Hispanic or Latino, 14 percent non-Hispanic Black, 5 percent Asian American and Pacific Islander, and 3 percent as another race/ethnicity, including multiracial. One in ten is a student enrolled in college or other classes (11 percent), while 9 percent have served on active duty in the U.S. Armed Forces. Eight percent self-identify as lesbian, gay, bisexual, and/or transgender (LGBTQ).¹³

The pandemic significantly increased the number of family caregivers, especially in Black communities.* Black adults were more likely to become first-time caregivers during the pandemic. Among those caregiving for a year or less, one-third (34 percent) of Black caregivers said that they assumed their caregiving role as a direct result of the pandemic, compared to 25 percent of caregivers of all races/ethnicities.¹⁴

Eighty-nine percent of caregivers report caring for a relative, while 10 percent report caring for a friend, neighbor, or other non-relative. Caregivers with lower household income (less than \$50,000) more often report caring for a non-relative (14 percent) than caregivers with higher income (eight percent).¹⁵

Caregivers are also increasingly caring for more than one care recipient and are doing so for an increasing length of time. Twenty-four percent of respondents stated that they are caring for two or more individuals, up from 18 percent in 2015.¹⁶ More caregivers have also been caring for

*Individual identities include African American, Black/African American, and others, depending on the sample.

longer, with 29 percent reporting caregiving for five or more years in 2020, up from 24 percent in 2015.¹⁷

The unique challenges of caregiving for specific populations often create further hardship for those caregivers. Family caregivers of adults with intellectual or developmental disabilities (IDD) more often face an extensive duration of the caregiving role, which can be a lifetime endeavor.¹⁸ Ninety-two percent of caregivers of individuals with IDD have been caring for the care recipient for more than ten years, a percentage made even more staggering when the percentage of total caregivers who have been caring for their family member for less than one year is close to half—43 percent.¹⁹ Caregivers of individuals with IDD also more likely to experience health concerns that manifest over time for both the caregiver and the care recipient.²⁰ Caregivers of individuals with mental illness often deal with the care recipient having a history of arrest or homelessness.²¹

Additionally, other members of the family or community, such as children in the home, may be called upon to carry out care tasks. About half of caregivers say there are others who provide unpaid help to their care recipient. Among those who report the presence of other unpaid help, 14 percent say at least one of those unpaid caregivers is a child under 18.²² Beyond the estimated 48 million adult caregivers in the United States, an additional three to five million child caregivers may be standing in their shadows.²³

Impact and cost of caregiving

While many caregivers report that caregiving has given them a sense of purpose or meaning, these positive feelings often co-exist with feelings of stress and strain.²⁴ Caregiving often takes a financial, physical, and emotional toll on those providing care.

Financial impact

The economic effects of family caregiving can result in financial strain and have substantial financial consequences. One in five caregivers report high financial strain as a result of caregiving (18 percent). Four in ten have experienced at least one financial impact (e.g., leaving bills unpaid or borrowing money from friends or family) as a result of their caregiving (45 percent). Three in ten have stopped saving money (28 percent), and one in four have taken on more debt (23 percent), both of which could have longer-term repercussions on caregivers' financial security.²⁵

“(Another) issue that (caregivers) face are sacrifices to personal financial features. Many people have to withdraw from the workforce or go from full to part time. Personal finances are greatly impacted. I know this first hand because I had leave my employment to manage all of this.”

– Testimony from Caregiver JP

On average, family caregivers spend 26 percent of their income on caregiving activities.²⁶ The strain is even greater on individuals who are Latino or Black (47 and 34 percent of income, respectively), as well as on younger caregivers, who have had less time to work and build up resources (42 percent of income).²⁷ Nearly eight in ten caregivers report having routine out-of-pocket expenses related to looking after their care recipients, spending approximately \$7,000 out of pocket annually on care.²⁸

Six in ten caregivers report working while caretaking (61 percent). Most working caregivers report going in late, leaving early, or taking time off to accommodate care (61 percent). One in ten working caregivers have had to give up work entirely or retire early (10 percent).²⁹ Estimates of income- and benefits-related losses by family caregivers age 50 and older who leave the workforce to care for a parent are \$303,880, on average, over a caregiver's lifetime.³⁰ Additionally, LGBTQ caregivers report high financial strain more often than those not identifying as such (27 percent vs. 18 percent).³¹

In addition, caregivers' savings are eroding, with 22 percent having spent all of their personal short-term savings and 12 percent having spent all of their long-term savings (meant for retirement or education). Two in ten have left bills unpaid or paid them late (19 percent), while another 15 percent borrowed money from family or friends. Nearly one in four (23 percent) have taken on more debt. One in ten have been unable to afford basic expenses like food (11 percent).³²

Physical and emotional impact

Caregiving also takes a physical and emotional toll on family caregivers. Three-quarters of caregivers report that they feel strain at least sometimes, and this percentages rise when looking at stress levels regarding tasks that caregivers increasingly perform, such as pain management and mental health monitoring.³³

Furthermore, this strain is not uniform across different cultures and circumstances. For example, the Home Alone Alliance found nearly a third of Chinese caregivers indicate feeling extremely stressed managing a family member's mental health and related behavior, compared with less than 20 percent for other racial and ethnic groups.³⁴ A caregiver of an individual with IDD has the additional stress of managing fears about the long-term future of the care recipient after the caregiver's death.³⁵

Just as caregivers are diverse, interventions to meet their needs for support and guidance must also be diverse.³⁶ Caregiver needs depend on the situation of the caregiver and care recipient, and we must emphasize the importance of connecting caregivers to the right resources at the right time.

“How we support those caregivers impacts how well they can care for others.”

– Testimony from an Anonymous

It also important to highlight that more than half of caregivers (53 percent) of adults report feeling that they had no choice in taking on the caregiving role.³⁷ This feeling, combined with issues such as social isolation and the growing complex needs of care recipients, can lead to significant mental strain.

Caregivers who are socially isolated or have no choice about caregiving are more at risk for experiencing difficulties with complex care. Nine percent of caregivers reported having no one to talk to about private matters, and 20 percent reported having no one to call for help, with Black caregivers most at risk of being socially isolated and less satisfied with the quality of their social relationships.³⁸ These caregivers are at higher risk for caregiver burden. Family caregivers with fewer social connections and lower satisfaction with their social supports are at higher risk for a number of health issues, including experiencing more caregiver burden, depression, sleep disturbance, and poorer overall health.³⁹ This problem is especially prevalent in younger caregivers, with 27 percent of Millennial caregivers indicate they are not satisfied with the quality of their social relationships, compared to 20 percent of Baby-Boomer caregivers and eight percent of Silent-Generation caregivers.

Demographic trends

The 65-and-older population in the state is expected to nearly double by 2050, when older adults will make up 28 percent of the adult population. This boom is compounded by the fact that Americans are also living longer—by 2050, one in five older adults will be aged 85 and older—leaving them vulnerable to health problems and more in need of assistance.⁴⁰

At the same time, the number of potential family caregivers is declining. The caregiver support ratio has begun a steep decline, decreasing from a high of 7.2 potential family caregivers for every

person in the high-risk years (those 80 years old and older) in 2010 to 6.8 in 2015.[†] By 2030, as the Baby Boomers transition into old age, the ratio will decline sharply to four to one. It is expected to fall further to less than three to one in 2050, when all Boomers will be in the high-risk years of life.⁴¹

A 2018 study by the Residential Information Systems Project at the University of Minnesota reports that 2.28 percent of the population lives with IDD. In New Jersey, this translates to more than 202,000 children and adults. Of these individuals, 59 percent, or 119,480, live in their family home. Between 1998 and 2018, the number of individuals receiving Medicaid-funded LTSS more than doubled, with those living in the home of a family member increasing from 25 percent to 61 percent.⁴²

Perhaps unsurprisingly, many caregivers are not preparing for their own or their care recipient's future needs. About half of caregivers expect to be caring for someone in the next five years (54 percent).⁴³ Making plans for future care (such as instructions for handling financial matters, healthcare decisions, or living arrangements), however, is still not the norm among caregivers; just 44 percent of caregivers report their care recipient has these plans in place, and 45 percent have their own future care plans in place.⁴⁴

The U.S. is becoming more racially and ethnically diverse. Trends in the racial and ethnic makeup of the U.S. population highlight a shift in the upcoming generation of older adults and the value they place on diverse cultural heritages. Respecting traditions and cultural norms for all racial and ethnic groups is necessary to ensure that culturally appropriate care is provided.⁴⁵ Programs and services need to be developed in ways that include the needs and wishes of multicultural communities.

Work of the Task Force

Why we must support caregivers

The struggles that family caregivers face will continue to be a significant issue for New Jerseyans. While caregiving has existed throughout time, caregiving today is more complex, costly, stressful, and demanding than any previous time in human history.⁴⁶

In any given year, one in five American adults will provide unpaid care to a family member or other care recipient. Unpaid caregiving is increasingly prevalent, and the U.S. population continues to age and live longer with complex and chronic conditions. Providing care causes caregivers to experience stress on their time, health, family, work, financial well-being, and personal well-being. They may find themselves in need of information, resources, benefits, or programs, but these are often difficult to find, access, or afford. As they step up to help their care recipients, it is vital that our government steps up to support family caregivers.

Unpaid caregivers serve as a core piece of the health and LTSS systems, and they are the main source for long-term care for adults living at home and in the community.⁴⁷ Of key concern for policy makers and other stakeholders, as more people need care and fewer potential family members are available to provide that everyday help, is whether this arrangement is sustainable.⁴⁸

Without family-provided help, the economic cost to the state's health and long-term services and supports systems will skyrocket. Family caregivers perform unpaid care valued at nearly \$13 billion per year in New Jersey (\$470 billion per year nationwide), helping their care recipients stay

[†]The caregiver support ratio estimates of the number of potential family caregivers (those in their primary caregiving years, ages 45 to 64) for every person most likely to need LTSS (those aged 80 and older). The decrease in the number of potential caregivers per person is known as the "care gap."

at home.⁴⁹ The value of this care is significantly greater than the annual cost of Medicaid for institutional stays, and a shift in the burden of care to Medicaid would mean a shift onto the tax payers of New Jersey. A nursing facility can cost over \$130,000 annually, while an individual living in the community who is supported by a caregiver might be able to supplement the services provided by their family caregiver with a home health aide for under \$70,000 annually.⁵⁰

Without greater culturally competent aid for family caregivers, including support among the public and private sectors and across multiple disciplines, overall care responsibilities will likely intensify on individuals within families, placing even greater pressure on them. In addition, caregivers themselves require support to ensure that they do not suffer deteriorating health effects, financial insecurity, or a combination of the two. There is an opportunity for public health experts, policymakers, health and social service providers, researchers, employers, financial institutions, and other stakeholders to work together to improve the health care and LTSS systems so that they better address the needs of caregivers. Together, we can develop and enact solutions to support family caregivers and to improve their well-being and the well-being of those for whom they provide care.⁵¹

The work to improve the experiences of caregivers is not just going on in New Jersey. On a national stage, the RAISE Family Caregiving Advisory Council has been working to develop their National Family Caregiving Strategy. The RAISE report, published in 2021, showed the importance of recognition for the hard work caregivers do every day; it also promoted awareness, outreach and education for caregiver services through the following categories:

- The importance of caregiver wellness.
- The importance of keeping caregivers as integral partners in any conversation that impacts them or their care recipients.
- Increase access to supports.
- Training and education for caregivers directly.
- Planning ahead for emergencies and the future.
- Financial and workplace security for caregivers.
- Increased research and data gathering into caregiving and the world of caregiving.⁵²

The recommendations of this Task Force fall in line with the national RAISE Family Caregivers Act Advisory Council report published in 2021. In order to best serve the specific needs of New Jersey caregivers, however, the Task Force first needed to hear from the State's caregiving population.

Task Force deliverables

Given the increased attention and assistance the State must give to its growing population of family caregivers, this Task Force was charged with developing recommendations for the Legislature. In order to gather sufficient information to develop recommendations, this Task Force was also responsible for completing three deliverables throughout its tenure:

- Developing and disseminating a survey of caregiver characteristics;
- Soliciting input and testimony directly from New Jersey's caregivers; and
- Researching and compiling an inventory of resources available to caregivers in New Jersey.

The Task Force met monthly between October 2020 through March 2022. During these meetings, the Task Force learned about the caregiver-focused work of the other Task Force members. They also invited a number of caregiver support/resource groups to present, such as Rutgers COPSA Institute Care2Caregivers, United Way of Northern NJ Caregiver Coalitions, New Jersey Association of Area Agencies on Aging, the New Jersey Divisions of Developmental Disabilities; Medical Assistance and Health Services; Disability Services; and Mental Health and Addiction Services.

To achieve the three deliverables, the Task Force split into three corresponding workgroups. A more detailed account of their processes and results can be found in the next section of this report and in Appendices D, E, G, I and K, but a highlight of actions are as follows:

1. As required per P.L.2018. c.166, the Task Force developed a survey of caregiver characteristics. The survey was disseminated to caregivers throughout New Jersey between May 3, 2021, and July 2, 2021 (61 days), and received 907 responses. The survey, written at grade level 9.6, was offered in multiple languages (English, Spanish, simple Chinese, Korean, and Gujarati), and most surveys were completed in English. The call for survey responses was promoted through the Task Force's extensive stakeholder network and through the Department of Human Services' (DHS) social media. The Task Force would like to thank all of the caregivers throughout New Jersey who participated in this survey.
2. The Task Force, in conjunction with the New Jersey DHS, Division of Aging Services (DoAS), held three public testimony listening sessions virtually on March 6, March 10, and March 18, 2021. Forty-six caregivers provided on-camera or phoned-in testimony, and many others provided written statements via email. This call for testimony was promoted through the Task Force's extensive stakeholder network and the Department of Human Services' social media.
3. The caregivers who testified comprise a diverse group in terms of age, relationship to the care recipient, length of time caregiving, and other factors. Caregivers of individuals with intellectual or developmental disabilities outnumbered any other group. Many of the caregivers who testified cared for someone with multiple service and support needs.
4. The Task Force compiled an inventory of existing state policies, resources, and programs that are available to support or assist caregivers in New Jersey, developing a workgroup to complete the task.

The workgroup met biweekly for three months and divided the research into the following topic areas: COVID-19, culturally specific resources, emergency preparedness, financial resources, government organizations, healthcare supports and providers, long-term care facilities, missing resources/unmet needs, new caregivers, nonprofit organizations, quality of care, quality of life, resources for non-English speakers, respite, safety, and technology for family caregivers. Resources were compiled in a state document library and reviewed by the workgroup.

Task Force Findings

1. Caregiver survey: outcomes

The survey captured the county, age, race, language spoken, income, and employment status of the caregiver, as well as a number of other factors that would impact caregiving. Specific statistics from this survey are interspersed throughout the report; a complete list can be found in Appendix E. A few key statistics gleaned from the survey are highlighted as follows:

- The most common age range of caregivers completing the survey is 56 to 65 (39.6 percent of the sample).
- 8.9 percent of the survey respondents are Black, while 79.5 percent are White. 10.4 percent of the survey respondents are Hispanic, Latino, or of Spanish origin.
- One in four respondents care for more than one care recipient.
- One in five are the parent or guardian of a child under 21.
- More than half of the respondents have provided care for five years or more.
- More than half (55.9 percent) of the respondents are employed (full-time, part-time, or self-employed), while 32.4 percent are retired.
- 81.8 percent of respondents indicated that caregiving interfered at least somewhat with their ability to maintain or start a job outside of the home.
- 82.2 percent of respondents are not compensated financially for the care they provide. Of the 12.6 percent who responded they were paid, just 11.9 percent—thirteen respondents, or less than 1.5 percent in total—said they were paid for all of their time spent caregiving.
- 73.7 percent of respondents said their care recipient(s) received no financial support from programs that contribute to the cost of caregiving.
- 43 percent respondents cared for their parents or in-laws; 26.4 percent cared for their spouse, partner, or significant other.
- Using a 1-to-10 scale, the average stress level reported by respondents was 7.57, with 60.5 percent of respondents rating their stress levels between 8 and 10.

These responses, compatible with national caregiving trends, outline the challenges faced by this group. No matter how fulfilling and necessary the work can be, caregivers in New Jersey face significant emotional, social, and financial stress, and do so in ways that differ across demographic categories. Furthermore, the ways the State can help relieve this stress are shown to be as underused as their national equivalents; 11.1 percent of New Jersey caregivers say they have used respite services, even lower than the 14 percent national figure.⁵³ Overall, the problems caregivers face nationally are the problems faced by New Jersey caregivers, too.

That said, it is important to understand some of the limitations of this survey data. The survey responses were collected as a convenience sample, which means the group responding to the survey was likely connected to community-based advocacy organizations. The survey was disseminated and completed online, which may have impacted the number of individuals who responded and their diversity.

Although the survey was translated into multiple non-English languages, the sample failed to capture many caregivers with lower English fluency and literacy; this is perhaps due to the fact that this survey is written between a ninth- and tenth-grade level literacy in English. This is further shown through 10.4 percent of the survey respondents being Hispanic, Latino, or of Spanish origin while the same group makes up 20.9 percent of New Jersey's population.⁵⁴

The Task Force would like to thank those involved in the creation and analysis of this survey, which was prepared by the members of the Task Force in coordination DoAS. Data was collected with assistance from Sean Karyczak, MS, CRC Pre-Doctoral Fellow at Rutgers, the State University of New Jersey, Department of Psychiatric Rehabilitation and Counseling Professions. Analysis was prepared by Stacey Callahan, New Jersey Department of Human Services, Office of Research & Evaluation. The Spanish-language survey was prepared by Migdalia Quesada,

Department of Human Services. The survey translations into Gujarati, Korean, and Simple Chinese were completed by Indus Translation Services.

2. Input and testimony from caregivers

Specific quotes from these testimony listening sessions and written submissions are interspersed throughout this document, and a summary of the input from all caregiver testimony, written and oral, can be found in Appendix G. The most prevalent themes that arose from the testimony are listed as follows:

- **Lack of access to information and resources for caregivers:** Caregivers report either that they don't know where to go to find out about help or that the avenues to finding help are prohibitively complex.
- **Lack of access to supports and services for caregivers:** Caregivers report that service systems are extremely difficult to access and navigate, and that their efforts to do so only exacerbate their monumental caregiving responsibilities. Caregivers report that they don't have the time, energy, resources, or understanding to fulfill all the requirements necessary to obtain services.
- **Experience with a weak caregiver support system, particularly for respite services:** Caregivers report that there are not enough paid care staff, and that these staff may not be adequately trained.
- **Experience with challenging financial and legal issues:** Caregivers report having to quit jobs, take reductions in pay, or decline the opportunity to accept better jobs because of their caregiving responsibilities.
- **Lack of available help for unique tasks:** Caregivers report a need for assistance with tasks that are difficult to complete due to existing service and support systems. These tasks include care for short periods of time (e.g., in the morning until the bus for school or the day program arrives), assistance with household tasks, and assistance with paperwork.
- **Lack of care that is shaped through a community lens:** Caregivers report that they would benefit from a holistic approach that looks at the needs and quality of life of the care recipient, caregiver, family, friends, household members, and others who are impacted by the care recipient.

“Being a primary caregiver for another person is extremely isolating”
–Testimony from Caregiver JB

Overall, caregivers reported feeling a sense of overwhelming loneliness, a feeling amplified by the complexity of reporting and paperwork, lack of instruction for care practices, limited caregiver support systems, inadequate paid care staff, and isolation as a result of increased responsibilities. This loneliness can shut them off from the world as a whole, and, as a result, they are less likely to see themselves as “caregivers”—a role filled by one in five people living in the United States and therefore one of immense potential affinity and solidarity. The need to “soldier on” alone can sometimes lead to greater determination, but it can also cut a caregiver off from potential support and aid. Based on the testimony and listening sessions, caregivers in New Jersey too often feel that soldiering on alone is the only option.

3. Inventory of resources

The workgroup tasked with developing a list of caregiver support services identified several challenges with how information is currently available:

- Supportive services differ depending on where you live. Different counties have different resources, different organizations service different parts of the state, and different funding streams for state services are based on care recipients' individual, and therefore different reasons for needing care.
- Existing information is not conducive to the needs of new caregivers. Many services use jargon unfamiliar to the public at large, which makes these programs not only difficult to navigate but also difficult to find in the first place. This leaves caregivers unaware of what support is available to them. It is integral that information is shared publicly in a manner that is easily understood by consumers.
- Information is presented in a way that makes it difficult to identify gaps in service and coverage, both regionally and based on conditions of the care recipient.
- Information on caregiver resources is not readily available in a web-based search, often existing only in PDF—or hard copy—form.
- Caregivers who care for multiple people (or for someone with multiple issues that span between departments and funding sources) have no one to help them coordinate between the different entities that cover their different issues. Eligibility rules, funding streams, terms of services, and other conditions all differ depending on whether one cares for someone with a mental illness, physical disability, chronic illness, IDD, or for an older adult. Healthcare for an individual with comorbidities is performed as a care team; a similar process does not exist for caregivers and care recipients whose needs stretch across and between state departments.
- Awareness of caregiving resources and services is not consistent across state agencies. There is an opportunity for improved information sharing and cross-agency communication on state-funded programs to foster coordination and collaboration to improve caregiver experiences.

Many of the members of this workgroup (and of the Task Force as a whole) are caregivers themselves. Despite the knowledge of human services in New Jersey and connections to the care workforce possessed by these members, they still experienced challenges seeking resources. The workgroup found that finding accurate information and resources requires knowledge of the structure behind services and of industry-specific jargon beyond even the professional level. This testimony is consistent with what was heard from caregivers during the Task Force's testimony listening sessions, in which the monumental duties of caregiving leave caregivers little time and energy to learn the new vocabulary and practices that seemed necessary to access services.

This exercise clarified the difficulty caregivers face in finding resources for their care recipients. Local, county, and state programs; nonprofits; private organizations; and other relevant agencies often have different criteria for the programs they offer, making finding information and services based on individual need confusing. Online searches for state caregiving resources are stymied by results existing solely as cumbersome PDFs or even hard-copy brochures. The resources themselves are often lengthy documents or clunky "phone book"-type materials that list potential agencies and phone numbers to call for information.

Throughout the Task Force testimony listening sessions, caregivers called for simple resource guides that show what services are available. The workgroup found this task challenging however, prioritizing simplicity for ease of navigation in its list (Appendix I) and would like to formally recognize the resource inventory developed by the RAISE Advisory Council (Appendix J). The exercise of developing a simple inventory of programs and services led to several of the Task Force's recommendations.

Overall findings

In the findings of all three workgroups, common themes emerged. In both the survey and the testimony listening sessions, caregivers told the Task Force that resources and supports were too difficult to access, a finding confirmed when looking to create the inventory. Similarly, the gaps in coverage found by the inventory workgroup—especially relevant to the 61.5 percent of survey respondents who cared for at least two different impairments—were the concern of the many testimonies lamenting the lack of help for unique situations and tasks.

Caregiving does not need to be a lonely activity, but the Task Force has found that, in New Jersey, loneliness is perhaps its defining quality. Testimony abounds from caregivers who wish they could connect with and learn from fellow caregivers (Appendix G). The lack of a unified online resource for caregivers implies the falsehood that their troubles are individual rather than systemic, and the complex professional language used by the resources that do exist drives them away instead of bringing them in.

Section 1 of P.L.2018. c.166, the law establishing the Task Force, outlined the challenges facing caregiving in New Jersey (see Appendix A for text); what was learned by the Task Force only emphasized how pervasive these challenges are and how devastating they can be. In conclusion,

the Caregiver Task Force, using nationally available data as well as new information generated by its workgroups, has identified a number of problems with the state of caregiving in New Jersey. These problems turn what could be an invigorating and rewarding role into a taxing and isolating one, and as the number of caregivers continues to increase, these problems will only intensify.

“It’s really necessary for us to work more compassionately and collaboratively to ensure more equity in delivery of services”

– Testimony from Caregiver SM

Task Force Recommendations

Such extensive problems, however, can be met with equally extensive solutions. In light of the challenge in front of them, the Task Force developed a number of recommendations for addressing the issues facing New Jersey in becoming a better state for caregivers and care recipients. These recommendations can be grouped into four broad recommendations:

- 1. Ensure that people know how to identify caregivers (themselves or others) and where to go for help.**
- 2. Clarify information on caregiving and caregiver programs while ensuring this information is easy to access and navigate.**
- 3. Expand availability of programs and services available to unpaid family caregivers, including respite care.**
- 4. Develop a more robust and effective paid care workforce to maximize support for unpaid caregivers.**

Framed within these larger categories are a number of smaller, specific recommendations. (See Appendix B for a comprehensive list of all recommendations.) Although some of them work as steps in fulfilling their larger recommendations, they have been written to be fully actionable on their own. Given the extensive reach of the four main recommendations, the Task Force thought it helpful to break down the course of actions into more immediately workable steps—steps that provide valuable aid to caregivers and care recipients independently.

Recommendation 1: Caregiver Outreach Campaign

There are an estimated 1.1 million caregivers in New Jersey.⁵⁵ Caregivers are all around us. They are our neighbors, friends, family, and coworkers. Caregivers assist individuals with a variety of needs from a myriad of different causes. Yet despite their omnipresence in the state, caregivers infrequently identify themselves as such.

One of the biggest challenges in supporting family caregivers is identifying them, or having them identify themselves. A theme that arose repeatedly throughout hours of caregiver testimony was that family caregivers are so dedicated to caring for their care recipients that they may not even know they are caregivers. Even if they know the terminology, they may not know that they are eligible for certain services, in addition to any services that may be available to the care recipient. Even if they are aware of the services available to caregivers, they may be too busy or isolated to pursue them. And even if they have the time or energy to look for these services, they may not feel comfortable asking for them—if they know who or how to ask.

The Task Force identified a crucial first step in supporting caregivers in New Jersey: identifying caregivers and bringing them to the forefront of the care conversation through a public awareness campaign.

Recommendation: *Develop an outreach and public awareness campaign*

The Task Force recommends the development and implementation of a public awareness campaign that will help identify caregivers and ensure they know where they can get help. This campaign must embrace diversity, equity, and inclusion to clearly define what a caregiver is, with all its facets and nuances, so that caregivers—along with society at large—can recognize the unique and priceless support they provide to their care recipients and the community. Through testimony listening sessions and survey responses, the Task Force gleaned that each caregiver has their own unique set of circumstances and challenges.

Although caregiving looks very different from family to family, the limitations experienced by caregivers and our need to support them remains consistent. Regardless of an individual's reason for becoming a caregiver, the length of time that someone has been a caregiver, or the care recipient, caregivers share a number of characteristics and needs common to all caregivers.

The goal of this campaign will be to ensure the unique needs of each caregiver are addressed while centering the characteristics that will allow as many caregivers as possible be able to identify themselves as such. Through a coordinated effort between the State, county agencies and local community-based organizations, caregivers of all kinds will begin to feel understood and supported.

The focus of the public awareness campaign will be:

- Defining and identifying caregivers;
- Identifying where to ask for help; and
- Describing types of available resources and supports

Defining and identifying caregivers

The campaign will educate the public about caregiving and enumerate the variety of caregiving situations and diversity of caregivers.

Ensuring that caregivers receive necessary services can be challenging. Caregivers struggle to find support and services because they do not know exactly what they are looking for, nor do they

fully understand what the role of caregiver will entail. When an individual becomes a caregiver, they are not handed a manual that explains how to be successful in navigating this role, what help they need to ask for to achieve this success, and the nuances of their new position. Becoming a caregiver can happen in a variety of ways: some individuals become caregivers the day their children are born with a disability; others become caregivers when their parents grow older and need care; still others become caregivers when their siblings are diagnosed with a chronic mental illness in mid-life.

The Task Force has found that caregiving is a spectrum. There are differing reasons, time commitments, and intensities of care for each care recipient, and such qualities can change. A caregiver may enter at one point within the caregiving spectrum but they can later change positions based on the needs of the care recipient. The need for caregiver support is constant, but because the intensity of that need is always in flux—because there is no fixed level of care a caregiver provides—it may be difficult for a caregiver to define themselves as such.

The most basic priority for the recommended public outreach campaign will be to inform the public that, no matter one's place on the spectrum, a caregiver is someone who provides care. Professionals who interact with families on a regular basis, such as teachers, primary-care physicians, specialists, psychiatrists, and social workers, should also be a target audience of the campaign so they can understand who a caregiver is and where to refer them to get services. Employers can also be a key audience for the campaign, to gain a better awareness of who caregivers are and recognize the support many of their employees may need.

Identifying where to ask for help

Challenges in identifying where to look for help was an issue that the Task Force identified in both caregiver testimony and survey responses. The public awareness campaign will work to promote improved navigation tools as outlined in Recommendation 2.

Identifying and describing available resources

Even when a caregiver comes to the realization that they are a caregiver, the individual may not be aware that services may be available for both themselves and for the care recipient.

In addition to identifying members in the community who are caregiving in isolation, the campaign is also interested in bringing forward those who know they are caregivers but may not know that they can access support services. Clarifying that there are services that caregivers are entitled to—and worthy of—is critical.

Many caregivers do not know where to start when seeking services. Others who have been connected to services do not know where to go when they do not receive the proper services or when additional services are needed. The public awareness campaign will work to promote existing and new services.

During the Task Force testimony listening sessions, caregivers called for increases in and improvements to assistance directed at care recipients. Assistance for care recipients also helps the people who care for them, so the promotion of existing services for recipients will also be a part of the campaign.

If the care recipient is being cared for by paid care staff (either in or outside of the home), the caregiver is available to focus on their own needs and more actively participate in society. Services like day centers and programs; physical, occupational, and psychological therapies; and visiting nurse services offer support that the caregiver may not be trained to provide. Family caregivers, according to the journal *Dimension of Critical Care Nursing*, increasingly “are providing complex acute and chronic care, and many are not prepared to do the tasks they are

expected to do.”⁵⁶ Paid staff and services can ensure this kind of care is done in a professional manner, which gives peace of mind for both the care recipient and caregiver.

Regarding services for the caregiver, many caregivers put the care recipient first. The loudest calls for help from caregivers are for services directed toward the care recipient, and they are willing to forego their own needs in order to prioritize care for the care recipient. Their selflessness is laudatory, but it often results in caregivers’ forgoing their own needs and desires.

Respite, counseling, and emotional and physical support for the caregiver are all vital to the long-term success of care in the community. Without this support, caregivers will burn out and no longer be able to provide care, which will leave the care recipient in a taxpayer-funded institution, such as a nursing home. If support is not given to caregiver, the system will collapse, but in order for caregivers to use this support, it must be publicized. As described in Recommendation 4, the Task Force is aware of the changes that need to be made to New Jersey’s paid care staff system.

“It’s hard to always know what we need or want to find or ask for and in some ways there’s a lot out there and in other ways there isn’t”

– Testimony from Caregiver AT

Recommendation: *Increase awareness of paid family leave benefit through the public awareness campaign*

The campaign need not wait for administrative reorganizations or information centralization to act; the Task Force has identified specific State programs that already exist but could benefit greatly from the increased awareness a dedicated campaign could provide.

An example of this is New Jersey’s Paid Family Leave Benefit. Legislation signed in February 2019, P.L.2019 c.37, increased the benefit of paid family leave. Eligible workers can now collect 85 percent of their weekly pay, capped at \$993, for twelve weeks. That is an increase from six weeks of benefits equal to two-thirds of their pay, up to \$650 a week. Instead of receiving a maximum of \$3,900 over six weeks, applicants could be eligible for as much as \$11,916 over twelve weeks. That amounts to a weekly increase of \$343 in addition to the additional six weeks of available benefit.⁵⁷ Although this will only serve caregivers who are eligible for family leave benefits, it is a valuable resource for caregivers who must leave work in order to care for their care recipient.

Many caregivers, however are still unaware of this legislation. Only 53 percent of New Jersey residents said that they were aware of the state law that provides access to paid family leave benefits, according to a Rutgers University study on the subject.⁵⁸ Such knowledge is stratified by income, with only 43 percent of residents earning under \$100,000 annually saying they knew about the law, compared to 65 percent earning \$100,000 or more.⁵⁹

The Task Force recommends that there be greater public information disseminated about the Paid Family Leave Benefit, including specific examples of how the benefit can assist caregivers.

Recommendation 2: Offer Navigation Support to Caregivers

The responsibilities of caregiving poses challenges to accessing services. Caregivers are often unable to leave the care recipient alone or are concerned about doing so. This often interferes with the ability of the caregiver to seek out and access available services.

This can also make travelling to services difficult, which poses challenges to accessing services that require in-person attention. Virtual services offer the benefit of being accessible directly from

one's home, yet many caregivers are not comfortable or familiar with using the technology required to participate in internet-based services.

The caregiving system is extremely complex, and caregivers desperately need assistance in navigating it to access services. Throughout the Task Force testimony listening sessions, caregivers expressed difficulties in navigating and accessing the caregiver services provided by both the State and other community-based service providers. There is limited awareness of the availability of State respite services, and the current financial criteria required to qualify for those services is also a deterrent. Respite services, further explained in Recommendation 3, is just one example of a service that caregivers repeatedly described as being difficult to understand and access.

Caregiver feedback consistently conveyed that the COVID-19 pandemic greatly exacerbated these service access issues, to the point where services have been either completely inaccessible or unidentifiable. As the result of the pause on all in-person activities, however, virtual service delivery became much more common. It is essential that we take advantage of this shift in expectations and create better technological pathways for caregivers to access services and resources.

Caregivers need to know that services are available, what those services include, and what the applications for those services entail, including eligibility requirements, and such needs will be filled by the public awareness campaign described in Recommendation 1.

Yet access is more than a simple matter of pointing in the right direction—once they find the services, caregivers must also be able to easily use them. The Task Force has found that New Jersey caregivers find service requirements overly complex, and simplification is required. Such a simplification process, however, must be done in a coordinated fashion between the relevant agencies to the extent allowable by the parameters set by the federal government.

At present, locating programs and services is unduly cumbersome. Information about available resources is not located in a centralized place, and no singular agency is responsible for maintaining information, supporting caregiver needs, or determining eligibility for caregiver programs. As a result, it is difficult to identify where there are gaps in services, why some programs are underutilized, and why others are overused.

Throughout the Task Force testimony listening sessions, caregivers repeatedly cited problems finding the help they need, both when they need it and in a way which they can receive it. In the Task Force survey, one in four respondents rated their ability to find resources for caregiving needs between 91 and 100 (with 0 being very easy and 100 being very difficult). Some testified that services are available in some counties but not others. When services are available, some required transportation that respondents don't have, needed additional administrative paperwork that the provider wasn't willing to complete, or included staff training that did not meet the level of need for the care recipient.

To truly support caregivers and their care recipients, significant improvements must be made to facilitate navigation of services and resources. The average New Jerseyan should be able to easily determine the availability of caregiver programs that will assist them and find the steps necessary to engage those services. To achieve this goal, service systems must be simplified and transparent. There must also be an ongoing commitment and greater investment in caregiver outreach and education. Increasing these investments of money, energy, and resources in caregivers is an investment in the health care infrastructure and financial stability of our State. When caregivers are able to access resources that allow them to provide care, they take stress off of the healthcare system.

Recommendation: *Establish a Caregiving Hub within the New Jersey Department of Human Services that serves as a navigation resource for caregivers seeking information.*

There are over 1.1 million caregivers in New Jersey; they provide nearly \$13 billion in unpaid care to their care recipients while helping them to remain at home and out of costlier taxpayer institutions.⁶⁰ Yet there is no singular state entity responsible for coordinating services and ensuring that caregivers have access to the supports they need for themselves and for their care recipients.

The Task Force identified the following issues within government and privately run websites that can be readily addressed to ensure that online searches are useful in identifying and connecting caregivers to supports and services:

- The use of industry-specific jargon and terminology causes family caregivers to have difficulty identifying the best search terms to yield accurate results.
- Online searches for state caregiving resources often result in cumbersome PDFs, hard-copy brochures, and booklets—clunky “phone book”-type materials that list potential agencies and phone numbers to call for information. These documents need to be adapted for online searches and updated to directly connect caregivers to the information that they need.
- Local, county, and state programs; nonprofits; private organizations; and other relevant agencies often have different criteria for the programs they offer, making finding information confusing. Whenever possible, these entities should work together to ensure their programs are integrated.

The previously cited “Caregiving in the U.S.” report found that the most common reason caregivers go online is to find more actual, hands-on help, specifically searching for in-person services, aides, facilities, or other help.⁶¹ The State should develop and maintain an integrated statewide consumer-facing database that caregivers and those assisting caregivers can use to identify resources and services. As mentioned above, the Inventory Workgroup of the Task Force focused on identifying and cataloging resources and services that are available to caregivers throughout the state and determined that it is difficult, if not impossible, to find key information about caregiving online. The Task Force also determined that many existing resources are not in formats that are suitable for online searches (e.g., links to PDF resource catalogs). This creates an unnecessary barrier for caregivers who are trying to identify services.

An example of a current online resource tool is the adrcnj.org website, which was developed by DoAS as part of the No Wrong Door (NWD) initiative for the State’s Aging and Disability Resource Connection information database. Although this tool is helpful, it is not the dynamic resource necessary to assist caregivers that the Caregiving Hub will be.

The Task Force recommends that the State of New Jersey create a Caregiving Hub that will serve as the first point of contact for caregivers and be accessible through a well-marketed, intuitive, consumer-friendly website. Caregivers have indicated that one of the most common supports they need is assistance in navigating forms, paperwork, and eligibility for services.⁶²

Thus, the purpose of the Caregiving Hub is twofold:

- Promote interagency connectedness among State agencies to share information and collaborate. Strong working relationships between state departments will help to integrate the multiple agencies that provide services and supports to caregivers.

- Serve as a point of connection for caregivers. The hub will act as a point of entry for caregivers looking for a knowledgeable resource on available services and ways to overcome barriers to accessing and utilizing services for themselves and their care recipients.

The hub will connect caregivers to knowledgeable navigators and navigation tools that allow caregivers to work with state and local resources to get answers. The Task Force recommends that the hub include information on state and local programs, and be regularly updated with local, county, and statewide agency information, as well as nonprofit, academic, and private organizations who support caregivers. The hub will need to be built in the spirit of diversity, equity and inclusion and should include information for people of all backgrounds who speak many different languages. (6.9 percent of the New Jersey population has limited English proficiency, and reaching this population is integral.⁶³)

The Caregiver Hub will help troubleshoot issues that arise for caregivers, including problems with using technology, affording the cost of services, and accessing transportation. In order to identify improvements or additional necessary supports, the hub will be updated with information that reflects the diversity of New Jersey's caregiving population through information gathered in focus groups and surveys. The feedback obtained from these methods will be shared publicly and will include recommendations and plans of action for improvements.

Recommendation: *Simplify available caregiver services*

The Task Force recommends simplifying all processes caregivers must go through to access services for themselves and their care recipients. Processes required of caregivers must be simplified in order for caregivers and care recipients to access state- and community-based care services. This simplification must include technological and non-technological pathways to learning about programs and services, determinants of eligibility, and application and enrollment processes.

Furthermore, guidance to caregivers about how to apply for services must be improved. In order to best fast-track caregivers to initial services or recertification/reauthorization, awareness of and access to simplified applications and enrollment processes are necessary. Applications for programs that serve caregivers and care recipients should be clear, simple, and available in multiple modalities (online, paper, mobile). Caregivers need to know how to complete applications and which applications are necessary for which services.

Recommendation: *Make it easier for caregivers to find available services*

The Task Force recommends the development of processes that make it easier for caregivers to find available services. One easy-to-implement pathway for improving the ability of caregivers to find information and services is creating direct access to knowledgeable staff through the highlighting of phone numbers on resource materials. Another avenue is by updating New Jersey state websites to include simplified navigation, accurate information, and clear instructions to help caregivers gain access to specific services and resources, with pre-qualifying criteria clearly outlined.

The public awareness campaign (Recommendation 1) will serve as a tool for service providers to directly connect caregivers to the services and resources that they need. Furthermore, the Caregiving Hub can ensure uniformity among information shared among caregivers.

“Families do all the research on available services, so if they don’t have the ability, tech. or time, it becomes much harder for them to gain access.”

– Testimony from Caregiver LG

Recommendation: *Convene a caregiving stakeholder and service “network of connectivity”*

Another way of achieving ease of access and navigation is through the creation of a better network of connectivity among service organizations and agencies. Committed, collaborative partnerships between state and local organizations are key components of this network. Members of this Task Force and other key New Jersey caregiving stakeholders will orchestrate connectivity through regular meetings and collaborations of a network of connectivity, such as a New Jersey Caregiver Coalition. The group will include local, county, and State agencies and nonprofit, academic, and private organizations who support caregivers. Direct input from caregivers will inform the priorities and accomplishments of this network.

The Task Force also makes an appeal to all caregiver service providers across New Jersey (not just the future members of the network of connectivity) to share information about all caregiver services, refer caregivers to those resources, and provide up-to-date web links and phone numbers to help state residents access accurate information

Recommendation: *Identify a “caregiver program specialist” within each relevant state agency.*

Although several state agencies include one or more caregiver programs, there is no single person or entity within state government who is required to be familiar with each program, nor is there any person or entity able to identify the staff expert on each program. This lack of centralized knowledge creates an enormous information gap and results in missed opportunities to assist caregivers.

Family caregivers support their care recipients with a wide range of tasks and activities, but the reason why they are providing care often dictates which services they can access and how they can access them. For example, if a caregiver were providing care for someone with a chronic illness, the care recipient could be eligible to receive supports through the Medicaid LTSS program. If the care recipient were born with an intellectual or developmental disability, however, the individual would need to seek the services through both the Division of Medical Assistance and Health Services and the Division of Developmental Disabilities. This situation includes even more agencies when the individual also has a mental illness. Unique programs have different eligibility requirements, as well as different income and asset limits, and they are funded by different sources. This can make it difficult for care recipients to get the help they need.

Caregivers are also increasingly reporting that they care for more than one individual, each with multiple comorbidities that require care (up from 18 percent to 24 percent from 2015 to 2020).⁶⁴ This makes it likely that there are multiple agencies the caregivers must contact, all with different staff, applications, service limitations, and eligibility guidelines. The ability to share and coordinate

information between agency experts is critical to ensuring caregivers can access the correct information when they need it.

Each agency that works with family caregivers should identify a caregiver program specialist within its office. These specialists would be responsible for maintaining and updating the Caregiving Hub and liaising with other caregiver program staff, and supporting training on navigation tools. The caregiver program specialists should be well known across agencies and available to navigators and other State staff to answer questions about caregiver support services, help troubleshoot issues facing caregivers, and assist navigators in understanding the nuances of the program, such as eligibility requirements and the application process.

Recommendation: *Conduct a study on strategies for establishing rates and evaluating compensation of paid care staff.*

New Jersey should ensure that when caregivers are looking for specific services, there is no wrong door for them to enter and no wrong phone number to call. The training initiative should aim to improve the knowledge and navigation skills of staff and volunteers at local, public and private organizations serving caregivers and care recipients. The goal of the training should be to ensure the workers serving caregivers and helping them navigate their caregiving journey are aware of the full array of services available to caregivers and the best ways to assist caregivers in accessing those services.

The training initiative will be implemented in coordination with the organizations and local/county agencies that already provide assistance in navigation of resources and to provide services to assist caregivers. These groups include local government entities like the Area Agencies on Aging/Aging and Disability Resource Connection (AAA/ADRC), county Mental Health Boards, county Offices of Disability Services, county Welfare Agencies/Boards of Social Services, and local Departments of Human Services, as well as the large network of community-based organizations that provide assistance on a daily basis. In addition to understanding caregiver needs and available programs, it is essential that local organizations understand the purpose of the Caregiving Hub and know how to utilize the navigation tools to assist with consumer needs.

Training will be provided to ensure that all organizations and agencies are aware of supports and services available and that the staff of these organizations know how to connect caregivers with services and keep service information up to date. Priority should be given to supporting existing organizations, especially those that serve communities of color, LGBTQ individuals, and diverse cultures.

Initiative should train professionals how to reach caregivers. Another priority of the Task Force is to help society at large understand the role and prevalence of a caregiver. The value that caregivers add to not just their own families but the world as a whole, needs to be recognized and appreciated by the communities in which they live and work.

Professionals who interact with families on a regular basis, such as teachers, primary-care physicians, specialists, psychiatrists, and social workers, should be a targeted audience of training initiatives so they can understand who a caregiver is and where to refer them to get services.

Recommendation: *Develop an awareness campaign to educate employers on the complex needs of caregivers.*

Maintaining employment can be incredibly challenging for caregivers. Many caregivers cannot afford to be a caregiver 24/7; others simply want to balance the responsibilities of caregiving with a career. New Jersey's largest employers should be educated on the challenges their employees face due to their caregiving roles and on ways to support their caregiving employees.

In collaboration with the New Jersey Department of Labor, an educational campaign should be developed to improve the way employers understand the needs of their employees who are caregivers or who may become caregivers. Employers should provide more flexibility that enables caregivers to continue to work despite their unique and unpredictable challenges. For example, the COVID-19 pandemic and resulting shutdown illustrated that flexible work environments and schedules are a viable solution to certain employment barriers; such environments could allow caregivers to best fulfill their roles as both worker and caregiver.

Recommendation: *Develop and implement a statewide caregiver assessment tool.*

While caregiving is a labor of love, caregivers face enormous challenges while providing support for their care recipients. As previously mentioned in Recommendation 1 of this report, caregivers from all walks of life may find themselves in their new roles suddenly and with limited knowledge of available services.

To better support family caregivers, the Task Force recommends that the Department of Human Services develop or identify and implement a caregiver assessment tool designed to assess caregivers' health, well-being, and the services and supports needed to prepare for their caregiving roles.⁶⁵ This assessment can be utilized broadly by any managed care organization, provider, or other social service agency to which the caregiver reaches out for help.

Recommendation: *Use the New Jersey Caregiver "network of connectivity" to coordinate caregiving lessons learned from the COVID-19 pandemic*

This Task Force convened in the midst of the global COVID-19 pandemic. The pandemic circumstances were unprecedented, making the challenges of caregiving even more complex. Many of the issues caregivers face brought to the fore by the pandemic in fact existed before it arose, but some were exacerbated by the pandemic. The COVID-19 pandemic has presented unforeseen challenges for all New Jersey residents, but family caregivers have faced unique challenges that impact their ability to provide the necessary care for their care recipients. Juggling work and caregiving responsibilities is not a new challenge for caregivers, but the pandemic added yet another layer of difficulty to this already-existing challenge. All congregate and interactive settings, like respite care and adult day care programs, were temporarily closed during the pandemic, leaving caregivers without any breaks or down time from a now-24/7 role. With no other options available, some caregivers made the difficult decision to place their care recipients in institutional settings.

One service particularly hard-hit by COVID-19 was respite. Respite has historically been an underutilized service, and the pandemic only intensified its reasons for underuse. For one, COVID-19 restrictions limited the ability and willingness of care workers to provide respite services. In testimonials and surveys, some caregivers shared concerns about letting care workers into their homes and going out of their homes themselves for a rest or break, at the risk of potentially exposing their care recipients to infection.

Adult day care services are an important option for caregivers who are willing or able to keep their care recipient living at home but have obligations during the day. Not only do adult day care

centers provide essential caregiver support, but they also provide important social engagement opportunities for care recipients. It is important to raise awareness of such services and to continue to explore methods to expand the number of state-approved adult day centers equitably across New Jersey's full geography.

Another caregiving structure affected by the COVID-19 pandemic were assisted living facilities, long-term care facilities, and skilled nursing facilities. Because they were hit so strongly by the pandemic's effects, many families opted to take their care recipients out of or avoided placing them in these settings. Limited resources for care during the pandemic, and concerns about the safety of the options that remained open, resulted in an increased number of adults taking on the full-time role of family caregiver and therefore being unable to work at all.

Although the Task Force survey and testimonials provide a snapshot of the alarming impact that the pandemic has had on caregivers' physical, mental, and financial health, research must be initiated to capture the unique toll that the pandemic has taken on caregivers.

Juggling work and caregiving responsibilities is not a new challenge for caregivers, but the COVID-19 pandemic added another layer of difficulty to this pre-existing challenge. Caregivers had been isolated for years before COVID-19, but the pandemic drastically and suddenly increased their social isolation. The increased and protracted solitude brought to light just how important human interaction and social engagement are for caregiver well-being. We learned from the pandemic that isolation is a critical issue for caregivers, not only during times of crisis, but all of the time.

Finally, the State must take a look at its emergency response capacities that were so taxed by the pandemic. The Task Force recommends caregiving be a topic to be addressed by future Task Forces examining the efficacy of emergency services, disparities in healthcare access, and overall impact on our state's workforce and economy; including caregivers in emergency response planning; and putting emergency contact procedures into place that allow caregivers to have ease of access to local alerts and broadcasting of information during times of crisis or emergency.

Overall, the COVID-19 pandemic laid bare the fact that in times of crisis, the challenges caregivers experience every day are grossly exacerbated. The lessons learned through COVID-19 should inform plans for future emergencies and disasters, plans whose drafting and implementation must include caregiver input.

Recommendation 3: Caregiving Infrastructure Improvements

There are issues with family caregiving in New Jersey that can be aided by the greater public awareness and improved organization found in Recommendations 1 and 2 but which ultimately require greater action to be properly addressed. The Task Force found three especially pressing areas of concern and offers a number of recommendations to best solve the problems they present:

- Financial relief and infrastructure improvements to caregivers
- Caregiver support programs
- Respite care

Financial relief and infrastructure improvements to caregivers

The “Caregiving in the U.S. 2020” report found that one in five caregivers report high financial strain because of caregiving.⁶⁶ Three in ten caregivers have stopped saving, and one in four have taken on more debt, both of which could have long-term repercussions for the caregiver. What savings they do have are eroding, with 22 percent using up personal short-term savings and 12 percent using up long-term savings meant for items such as retirement or education. Two in ten have left bills unpaid or have paid them late (19 percent), while another 15 percent have borrowed money from family or friends. Unsurprisingly, when caregivers have a household income under \$50,000, they more often report having experienced negative financial impacts due to caregiving.

“There’s a real impact to caregivers from a financial perspective, not just the emotional...the weight of caregiving has such a weight on it.”

– Testimony from Caregiver A

Providing financial relief and infrastructural support for New Jersey’s caregivers is imperative. Caring for an individual who is sick, elderly, or has a disability, whether at home or in an institutional setting, is extremely costly, and there are numerous caregivers who provide the service at home with virtually no assistance from the State or federal government. On average, unpaid caregivers spend approximately \$7,000 out of pocket annually on expenses related to caring.⁶⁷

Recommendation: *Develop strategies to provide financial relief to households that pay or incur expenses for the care and support of a care recipient.*

All types of family caregivers face out-of-pocket costs each year on caregiving expenses that are burdensome for many. The state should consider strategies such as a caregiver tax credit and expanded program eligibility to provide financial relief to caregivers, including those who provide care for more than one individual, and those caring for people who are middle income and often do not qualify for assistance programs. The amount of money saved by the State when an individual is cared for by a family caregiver should be considered in any conversation surrounding caregiver finances. As mentioned in the Work of the Taskforce section, the cost of caregiving at home with the assistance of paid care staff is around half of the cost of a nursing facility. Assisting caregivers in these ways can reap long-term benefits for the State and for caregivers.

Recommendation: *Improve programs within DHS to focus on caregivers who do not typically receive services from the State.*

The Task Force recommends a review of eligibility criteria for caregiver programs. The systems that serve care recipients and caregivers need to be reassessed and updated so that individuals who are sandwiched between Medicaid eligibility and having the ability to pay privately are served appropriately. For individuals who do not meet Medicaid eligibility (or eligibility for other programs) but still struggle with paying privately for care and care-related expenses, financial assistance should be offered on a sliding scale. New Jersey currently offers some caregiver programs that offer cost-share options as a lower cost option for individuals who are not eligible for Medicaid long term services, such as Statewide Respite Care Program (SRCP), Jersey Assistance for Community Caregiving (JACC), and Alzheimer’s Adult Day Services Program (AADSP).

Recommendation: *Align eligibility requirements and services offered through State-funded home- and community-based programs which target caregivers or can assist caregivers.*

The State currently offers a variety of programs that support caregivers and offer respite, however, most have different income requirements, application processes, methods of evaluating assets, methods of evaluating needs, services offered, and sliding scales for co-payments. Caregivers are often overwhelmed when determining which program is appropriate for them based on the above complications, which can lead to an inability for them to receive the services they need. The sheer number and complexity of preconditions encourages people to make caregiver program decisions based solely on the amount of the co-payment instead of the services the programs provide. Furthermore, the programs have separate administrative structures, payment mechanisms, and provider networks, adding to the caregivers' burden of decision-making and accessing services.

During the Task Force testimony listening sessions, caregivers highlighted the need for simplicity in service provision. The confusion that we have outlined above related to these programs can be alleviated by aligning or merging the programs into one clear program that serves caregivers' needs.

Recommendation: *Expand legal service initiatives to assist caregivers in navigating the complex and often confusing legal circumstances they encounter.*

Caregivers frequently need help with a myriad of legal issues, including wills, guardianships, power of attorney/financial planning, eligibility, rights, advanced directives, estate planning, and trusts. Many times, caregivers do not know how to begin the process, or even what help they need in the first place. The Task Force recommends increasing access to free or low-cost legal services that assist low-income caregivers in navigating difficult circumstances, and recommends training for attorneys and advocates who serve caregivers and their care recipients.

Furthermore, the Task Force recommends an expansion of legal education, tools, and resources that assist caregivers to better address the legal issues they encounter and plan for care recipients. Initiatives like this empower the caregiver to plan for the future and be better prepared for inevitable changes in their life.

Caregiver support programs

During the Task Force testimony listening sessions, caregivers reported that they feel isolated and overwhelmed, and many are experiencing grief. Almost three-quarters (72.5 percent) of the caregivers who responded to the Task Force survey reported difficulty maintaining personal relationships and/or personal activities, and nearly two-thirds (63.2 percent) of caregivers reported finding it difficult to take care of their own health. In addition, more than half (51 percent) of the respondents to the survey indicated that they are functioning as caregivers 24/7, leaving little to no time for embracing healthy lifestyle habits that boost their overall quality of life.

On an airplane, when an oxygen mask descends in front of you, the first rule is to put on your own oxygen mask before you assist anyone else. Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important—and one of the most often forgotten—things one can do as a caregiver. When a

“Resources [and] funding is needed to create services such as support groups, respite, online information, stress relieving activities, hotline”

– Testimony from Caregiver CC

caregiver's needs are taken care of, the care recipient will benefit as well. Unfortunately, caregivers are struggling to access wellness services due to inadequate marketing, prohibitive costs, and inconvenient timings and locations.

Recommendation: *Increase and improve training, education and wellness programs directed at family caregivers.*

A caregiver that feels confident in their ability to care is a caregiver with higher self-esteem in all areas of their life. One way to boost that confidence is to offer trainings to caregivers on how to perform this role more successfully. Education and training on proper techniques for care allows caregivers to be more comfortable in their role. In addition to role-specific training and education, wellness programs that address the physical and emotional needs of caregivers are important. Wellness programs have been shown to improve caregiver physical and mental health, as well as reduce caregiver burden, but many caregivers are unaware of existing programs and their potential benefits. These resources need to be more effectively marketed to the caregiver population.

Caregiver training, education and wellness programs also need to be available in virtual or remote formats. More than half (51 percent) of the caregivers who responded to the survey indicated that they are providing care to someone around the clock, leaving little to no time to attend in-person programs. Virtual wellness offerings allow caregivers who are unable to leave their homes the opportunity to participate in much-needed outlets for both mental and physical well-being.⁶⁸ Health coaches are another method to motivate caregivers to access existing virtual wellness resources (tai chi, yoga, meditation, cooking demos, nutrition education, respite care, and others) that can improve their quality of life.

Recommendation: *Improve access to technology that will assist caregivers.*

Technology can help reduce the burden on caregivers, but not all caregivers have access to technology, know how to use it, or are motivated to do so. Therefore, programs that provide caregivers with critical technology, education on how to use it, and the support they need to make it a part of their daily lives are crucial.

In a 2018 AARP report on caregivers' technology needs, caregivers noted they were seeking technology that can provide peace of mind and wanted tools to ensure medications are managed accurately and with ease. That said, they were rightly concerned that the technological services for their loved ones that can help with these tasks should be of good quality and be dependable.⁶⁹ Given this information, and given caregivers' prevailing interest in technological solutions (especially younger ones), it is our position that caregiving innovations have yet to adequately meet caregivers' needs. Exciting opportunities exist in this massive market. The Task Force calls upon savvy innovators, investors, and product developers to pursue promising opportunities to meet the needs of New Jersey family caregivers and the millions of people they serve.

Recommendation: *Improve programs that offer social support to caregivers.*

Existing virtual and in-person caregiver support groups need to be offered with additional options. Within the larger category of caregivers exist different types of caregivers with different needs, so caregiver support groups tailored to the needs of a particular caregiver population need to be made available, whether it be by the living situation of the caregiver, the condition of the care

recipient, or any other relevant categorization. For example, a support group designed specifically for caregivers of care recipients with multiple sclerosis could give specific caregivers the opportunity to share experiences and resources with others in a similar situation, improving the quality of care overall. The mission of these support groups would be to create networks of caregivers that would promote relationship-building and mentoring.

Recommendation: *Increase services, particularly respite, that allow caregivers time to care for themselves.*

About half of respondents to the Task Force survey (50.3 percent) said that they would share their responsibilities with professional service providers if they could. Only 6.5 percent of respondents, however, indicated that they have actually used respite care services. A break from caregiving can enhance every aspect of a caregiver's life by improving mental, physical, and spiritual health. It allows caregivers the freedom to take part in essential activities like going to medical appointments, seeing friends, and going on vacation. Respite is a key component of ensuring the health and longevity of caregivers and, as such, is explored further in the following section.

Respite care

Respite is essential for all caregivers in order to strengthen and stabilize their caregiving situations. Family caregivers need quality, accessible respite services to meet planned and crisis needs. Current respite options, however, do not support caregiver choice and preferences and are prohibitively expensive. More supports and services that educate, inform, and support caregivers about the value of and options for respite care are needed. The Task Force recommends increased access to affordable caregiver services and supports, including respite care.

What is respite?

Respite care services provide caregivers with a break from caregiving and may be either planned in advance or provided in an emergency. Generally, "respite" refers to paid services (e.g., a home care provider, adult day services, or a short-term stay in a facility), but family and friends can be considered informal sources of respite. Caregivers use respite services to take a break from caregiving by engaging in activities like spending time with other family members, tending to their own health and hygiene needs, or taking a well-deserved break. Although respite is intended to be a break for the caregiver, some caregivers use respite for essential tasks, such as going to work or running necessary errands. Respite often involves paid care staff coming to the care recipient's home, but it can be provided in an out of home setting such as an adult day program.

Types of Respite

In-home respite

- Consumer-directed
- Home care services (skilled, non-skilled, volunteer)
- Volunteer programs

Out-of-home respite

- Adult day care or child care centers
- Provider's or other family's home
- Campership

Overnight respite

- Facility-based (nursing homes, assisted living, developmental centers, memory care homes)
- Campership
- Group Home based

The way respite is provided—whether in home through an agency or friend, at an institution, or at an adult day program—should be decided by the caregiver and care recipient. Respite services should not be prescriptive but instead available to caregivers when they need it and in the way they need it. The respite needs of caregivers cannot fit neatly into a box, and services must be diverse enough to meet the unique needs each caregiver. This is particularly important to consider when serving families who are ethnic or cultural minorities.

“The number one support for caregivers is respite.”

– Testimony from Caregiver LA

Although increased respite care is necessary, respite should not be used to supplant necessary services for a care recipient—it is not a panacea for other larger, structural issues with caregiving as a whole. If a robust service system existed and were readily available to support the care recipient, respite would be used in its intended form: to serve as a break.

To advance understanding of the value of respite, the 2015 ARCH National Respite Network and Resource Center workgroup on respite research defined respite care as “planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some measurable improvement in the well-being of the caregiver, care receiver, and/or family system.”⁷⁰

Respite is particularly important to caregivers who report high burden: 46 percent of highly burdened caregivers express an interest in respite care, compared to 32 percent of caregivers with medium or low levels of burden.⁷¹ Those who live with the person for whom they care, attend to a person with Alzheimer’s disease or other memory impairment, or care for someone with a mental health issue also show higher levels of interest in respite services.

During the COVID-19 pandemic, caregiving became exponentially more difficult. The suspension of many supports and services, as well as care recipients and caregivers’ being home together more often, compounded already-existing issues in caregiving. Because routine services for care recipients were halted or caregivers were concerned about service providers entering the home, most caregivers took on additional responsibilities. Some respite services were temporarily suspended, which meant the burdens on caregivers’ wellbeing, health, and stress levels—worse than ever in a time of higher-than-usual stress—were only exacerbated.

“Even for respite there are waitlists, which defies the definition of the word.”

– Testimony from Caregiver LA

How does respite benefit caregivers?

Although caregivers report significant emotional and spiritual rewards from the caregiving experience, they nonetheless experience physical and emotional stress as a result of the demands of caregiving responsibilities. The concept of respite as a supportive service is based on the premise that giving caregivers a break from daily, ongoing caregiving responsibilities will benefit their overall physical and emotional health and enable them to provide caregiving support for longer. Benefits of respite include:

- Reduces family caregiver stress levels, which benefits overall physical and emotional health;
- Improves family dynamics, stability, and well-being;
- Provides peace of mind to a caregiver when an emergency arises;
- Reduces social isolation of the caregiver;

- Reduces hospital costs and avoids or delays costlier foster care, nursing home, or other out-of-home placement;
- Reduces unnecessary institutionalization;
- Reduces risk of abuse, neglect, and exploitation; and
- Supports caregiver health and well-being, and may delay nursing home placement.

Several studies have found that respite improves family caregiver resilience and benefits their physical and emotional health. One study found that respite can improve resilience in caregivers of people living with dementia, which is often a particularly intense form of caregiving.⁷²

Respite services positively impact caregivers' health and wellbeing. For example, the use of adult day services as a form of respite lowers caregivers' exposure to stress by approximately an hour per day and lessens the care recipient's reactivity to problem behaviors.⁷³ This can reduce risk of illness and poor mental health among caregivers.

Single-service interventions, like respite care services, offer greater flexibility and adaptability to changing environments. Many caregivers, however, experience barriers to accessing these services.

Barriers to using respite

Despite its myriad benefits, respite remains an underutilized support for family caregivers. Caregivers who shared testimony with the Task Force feel that respite is desperately needed but not available.

Just 14 percent of family caregivers report having used respite, though 38 percent feel that it would be helpful.⁷⁴ One challenge is finding available respite services, a struggle that mirrors the challenges caregivers face in accessing information, education, and training. Some barriers to accessing respite services include:

- Limited availability;
- Limited government funding;
- High cost;
- Shortage of qualified providers (referenced in Recommendation 4);
- Limited respite options;
- Reluctance to use respite, ask for help, or self-identify as caregiver;
- Access issues;
- Program constraints;
- Lack of transportation;
- Multiple funding streams, each with confusing and restrictive eligibility;
- Lack of information and; knowledge about respite;
- Difficult applications; and
- Medicaid limits and other programs using income limits that do not reflect the needs of enough caregivers (as referenced earlier in Recommendation 3).

Because of the limited utilization of respite services, funds that would pay for respite come directly out of the budget for care recipient services. This forces the caregiver to choose between direct care for the care recipient or a service that would allow the caregiver to have a break.

Recommendation: *Increase the availability of high-quality, setting-appropriate, and caregiver-defined respite services to give caregivers a healthy and meaningful break from their responsibilities.*

Family caregivers often say that they need a break from caregiving, but the vast majority of family caregivers never use respite, citing barriers such as cost, availability, inconsistent provider training, and reluctance to leave their care recipient in someone else's care. Some care recipients also resist being cared for by an unfamiliar person. Ensuring the affordability, quality, and availability of respite care is a critical component of a holistic approach to supporting families.

Recommendation: *Improve availability and capacity of in-home respite service providers..*

A significant difficulty that caregivers face in scheduling respite services is a shortage of willing, qualified providers and varying definitions of respite. Even when a respite care provider is available, caregivers seeking in-home respite may be reluctant to schedule services because of concerns about lack of training and the skill level of the care provider. As will be mentioned in Recommendation 4, in-home providers are often left to face a wide range of challenges with little support and minimal training. When respite is scheduled as a one-time occurrence, in-home respite providers are even more likely to encounter unfamiliar demands. High staff turnover rates contribute to challenges in maintaining a trained workforce.

During the Task Force testimony listening sessions, families strongly recommended career advancement opportunities, including additional training, as a way to help to address the shortage of trained respite providers. This would promote worker retention and create a better trained workforce for care recipients with complex care needs. Improving the workforce in this way and others will increase availability of those providers. Cross-system provider training and education should be provided to ensure a skilled workforce.

Recommendation: *Increase the affordability of respite care options for caregivers.*

Respite care is prohibitively expensive for many caregivers and difficult to access. Access to affordable respite services is essential to supporting family caregivers. In addition, the current financial thresholds for eligibility preclude many income brackets from qualifying for state-based respite services. This Task Force recommends the development of respite programs that serve caregivers on sliding-scale fee basis so that all caregivers, including those of low-income levels, have affordable access to services. A sliding-scale fee system would allow for caregivers of all incomes to take advantage of respite programs that they would pay for at a level commiserate with their income.

Recommendation: *Improve the support of family caregivers during emergencies..*

Emergencies can encompass many events, including weather, pandemics, natural disasters, and economic instability. Family caregivers continue to support those who are the most at risk and

vulnerable during these times. Caregivers and care recipients can benefit from both short- and long-term emergency preparedness planning.

Larger formal systems exist throughout New Jersey for caregivers to use in crisis response, but they could be modified to specifically address the needs of caregivers. For example, localities utilize databases of individuals with access and functional needs who may need additional help during emergencies.[‡] Linking systems like these to caregiver needs during times of crisis would be valuable in coordinating support and response. Registries like these can also identify caregivers who need assistance developing emergency plans, which may help lessen the impact of emergencies on caregivers and care recipients.

Emergency situations that require extended and/or unplanned needs for respite care, such as the hospitalization of the caregiver, death of a close family member, or needing to care for another family member experiencing a crisis, should be as easy as possible to address. Having access to respite care during these emergencies helps the caregiver take whatever actions are required and have peace of mind. Emergency respite hours should be available and accessible for caregivers.

Recommendation 4: Care Workforce Development

While the primary focus of the Task Force is the needs of unpaid caregivers, the ongoing paid caregiver workforce crisis and its negative effect on caregivers and care recipients must also be addressed.

Individuals with access and functional needs rely first and foremost on family members, friends, and neighbors. These individuals comprise a collection of more than forty-three million caregivers whose economic contribution is valued at \$470 billion.⁷⁵ For caregivers who have limited local networks, are caring for those with more complex needs, or are in need of a break, paid care staff are a lifeline. Direct care workers are formally classified as personal care aides, home health aides, direct support professionals and nursing assistants, a broad array of job titles that we will refer to as paid care staff throughout this report. Paid care staff provide assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) across care settings. Their role requires considerable technical skill, especially as consumers' conditions change, and an extensive set of interpersonal skills essential for building relationships with individuals and their caregivers, communicating effectively with other members of the care team, and managing conflicts and crises.

The already-sizable paid staff workforce is expanding rapidly as our population grows older, people live longer with disabilities and chronic conditions, and the supply of potential family caregivers dwindles. The paid staff workforce has grown by 52 percent within a decade, from 3.1 million workers in 2010 to 4.6 million in 2020, and it is expected to add an additional 1.3 million new positions by 2029.⁷⁶ The majority of job growth will be in the home care sector, which is projected to add just over one million new jobs (46 percent growth).⁷⁷ The residential care sector will also grow substantively, adding 168,400 new jobs (23 percent growth), while nursing homes are projected to lose 19,300 jobs (three percent decrease).⁷⁸

Despite its steep increase, however, this growth is not keeping pace with the need for paid care staff. The direct care workforce will additionally need to fill 7.4 million job openings over the next decade as existing workers leave the field or exit the labor force altogether.⁷⁹ Combined with the projected growth stated above, nearly 8.2 million total paid care staff job openings are anticipated from 2018 to 2028. Best projections predict the home care workforce will have 4.5 million job

[‡] The State's [Register Ready](#) program is just one example.

openings, residential care will have one million job openings, and nursing homes will need to fill approximately 561,800 nursing assistant jobs.⁸⁰

As startling as these projections are, they do not tell the full story. First, the projections are necessarily based on the assumption that base year employment meets demand; this fails to account for existing job vacancies, which are poorly measured but widely experienced in the field. Furthermore, the projections do not account for anticipated or unexpected shifts in population health, family caregiving, the organization and delivery of health care and LTSS, among other factors (not to mention the impact of the COVID-19 pandemic).

The employment projections also do not account for the strikingly high turnover within each segment of the direct care workforce. Although there is no reliable national figure on turnover in the direct care workforce, it has generally been reported at 40 to 60 percent or higher.^{81,82} The most recent annual survey of private-duty home care agencies found that turnover reached a historic peak of 82 percent in 2018, a 15-percent increase from the previous year.⁸³ The ratio of paid care staff looking for another job, a proxy indicator of turnover, is one in four for nursing assistants in nursing homes and one in five for home health aides. Forty-five percent and 35 percent of these workers, respectively, report that they are somewhat or very likely to leave their current job within the next year.⁸⁴

Caregiver testimony during the Task Force caregiver testimony listening sessions reinforced the data summarized above and highlighted what provider agencies have been experiencing for several years: there is a significant paid care staff workforce crisis.

Several factors contribute to difficulties in hiring and retaining paid caregivers, including:

- Low wages;
- Few benefits;
- Long hours;
- Irregular hours;
- Physically and mentally demanding work;
- Numerous policies, rules, and regulations;
- Personal liability; and
- Limited career growth.

When combined with the increased demand for paid care staff, this has led to families spending large amounts of time searching for and training care staff, if they are able to find them at all. In addition, the constant turnover of paid caregivers is detrimental to the well-being of the individuals served. As a result, the role of family caregivers has expanded to include tasks that were once provided by care providers and medical professionals.

Recommendation: *Recognize and recruit paid care staff.*

The Task Force recommends changing the public narrative on paid care staff in order to effectively communicate the challenges caregivers face and build broader awareness and support to this workforce.

Public awareness messaging should be developed to improve the general public's understanding and respect of the direct care workforce. The public awareness campaign would focus on the following:

- Educate the public on caregiver services and what it means to be a caregiver;
- Increase positive attitudes toward care professions;
- Prioritize direct care workforce policy solutions;
- Support projects that empower paid care workers to tell their stories in their own words; and
- Strengthen the education-to-workforce pipeline in direct care.

This component of the public awareness campaign should focus on outlining the types of jobs included in paid caregiving, reflecting on the benefits of engaging in caregiving work, and promoting the field as a whole. One goal of the campaign is to increase the number of individuals in the care workforce and increase faith in the fact that those individuals can appropriately care for care recipients.

Recommendation: *Collect data on the paid care staff workforce.*

The Task Force recommends creating a robust workforce data collection system to better understand direct care workforce capacity and develop tailored solutions to pressing workforce challenges. This should be created in coordination with local research institutions as well as existing initiatives within the state of New Jersey that collect and analyze data on workforce issues.

The research should look into the root causes, scope, and severity of the direct care workforce crisis, as well as examine supervision methods, career trajectories, recognition of best practices, employment incentives, and recruitment of new workers. Input from paid care staff about how the direct care career ladder progresses and how the career path could be improved should also be included to add a prescriptive element to our data.

Recommendation: *Increase compensation for paid care staff.*

There are limited funding sources to pay for caregiver support. Many families do not have the financial resources to pay out of pocket for paid care staff in addition to other caregiving essentials, especially because unpaid caregiving already incurs increased costs for caregivers.

The Murphy Administration has dedicated funds in each annual budget, more than \$200 million in FY2023, to increase the wages of child care workers, direct support professionals, home health aides and personal care assistants, private duty nurses, mental health and addiction professionals, certified nurse aides and other nursing home employees. This includes an almost \$5-an-hour increase in DSP wages since 2019 and an increase to more than \$24 an hour for the home health aide/personal care assistant agency rate to help ensure our most vulnerable residents, including seniors and children with significant illnesses, continue to have access to quality, community-based care.

Despite these great strides, wages for paid care staff do not match the importance of their work. The Task Force recommends the following:

- Continue increasing wages to direct care staff to remain a certain percent over minimum wage, with annual built-in increases based on Consumer Price Index (CPI).

- Strengthen the social safety net and urge employers to increase access to workplace benefits (such as robust and affordable health benefits, paid leave, and retirement plans) for paid care staff.
- Evaluate the impact of wage increases on paid care staff, their employers, and New Jerseyans at large.

Recommendation: *Conduct a study on strategies for establishing rates and evaluating compensation of paid care staff.*

This study would conduct a comprehensive rate evaluation and make recommendations for establishing consistent rates among services that provide direct care. This work should be focused on attaining in equitable and sustainable wages for home- and community-based long-term care supports. Initial requirements of this rate setting system could include and entail the following:

- Systemic research into equitable and sustainable direct care worker wages;
- Transparency and consistency of wages across programs and settings;
- Built-in annual increases for rates based on Consumer Price Index (CPI);
- Development in conjunction with individuals who have expertise in rate analysis across the spectrum of service categories;
- A tiered system to recognize acuity levels/complexity of care that reflects the needs of the participant in a consistent, quantifiable, and transparent process;
- Holding harmless existing provider rates;
- Development of a process for identifying cost outliers; and
- State compliance with federal rules and regulations.

The study should consider the factors mentioned above and ensure fairness and equity across systems for workers, agencies, caregivers, and care recipients. The study should include interviews with representatives from the Departments of Labor and Human Services as well as academic research institutions, workforce representatives, care recipients, caregivers, and caregiver stakeholders in New Jersey.

Recommendation: *Train paid care staff on key competencies that improve care of the recipient and ease the worry of caregivers.*

During the Task Force’s testimony listening sessions, caregivers reported that many of the paid care staff that had cared for their care recipients lacked adequate training. As a result, caregivers are not comfortable leaving their care recipients in the care of the paid care staff. Such distrust has many knock-on effects. One example is an underutilization of respite services; a break for a caregiver is not a break if they spend the time concerned for the care recipient’s safety, and this had led many to forgo available respite services entirely. In addition, caregivers stated that finding caregivers adequately trained to care for individuals with complex needs was even more difficult.

The Task Force recommends the strengthening of training standards for care staff. Workers must be equipped with the depth of knowledge and skills required to meet the needs of today’s caregivers care recipients. To accomplish this, the Task Force recommends:

- Establishing an official State standard of competencies for paid care staff;
- Revising paid care staff training curricula to reflect the full set of skills needed for this field and reflect the competencies established above;
- Strengthening the training infrastructure to support adult learners and the attainment of meaningful direct care credentials at any age;
- Improve and expand direct care training delivery and training standard enforcement;
- Developing rungs in the career ladder that are accessible to paid care staff and build on their current experience; and
- Requiring regular supervision and/or coaching of care staff in order to maintain a quality workforce.

The paid care workforce in New Jersey consists of a variety of caregiving professions and care settings, each with different training requirements and competency standards. Currently there is limited consistency and portability of training for paid care staff. This training recommendation recognizes that multiple training options exist within the industry, such as facility- and community-based care. Therefore, this training proposal encourages flexibility to accommodate proven effective training options that are consistent with the identified standards of practice.

Conclusion

Caregiving is essential to the function of every culture and society. Almost everyone is, has been, or will be a family caregiver at some point in their life. Like New Jersey, caregivers are diverse, cutting across all generations, racial/ethnic groups, incomes, educational levels, family types, gender identities, and sexual orientations. Caregiving takes a physical, emotional, and financial toll on those providing care.

As stated throughout this report, caregivers are struggling with both a lack of resources and a difficulty understanding and accessing of the resources that already exist. Their relationship with the complex caregiving systems in New Jersey has left them feeling overwhelmed and alone.

This Task Force convened to

- Make recommendations for the improvement and expansion of caregiver support services;
- Develop and disseminate a survey of caregiver characteristics;
- Solicit input and testimony directly from New Jersey's caregivers; and
- Research and compile an inventory of resources available to caregivers in New Jersey.

These activities further solidified what the Task Force members already knew: that despite serving as the backbone of the State's care infrastructure, caregivers in New Jersey are greatly undervalued.

This report has given the opportunity for public health experts, policymakers, health and social service providers, researchers, employers, financial institutions, and other stakeholders to work together to improve the health care and LTSS systems so that they better address the needs of caregivers.

As such, the Task Force recommends that New Jersey legislators, state agencies and local organizations take the necessary action steps to achieve the above recommendations. Most importantly, the State must:

- 1. Develop a public outreach campaign for caregivers.**
- 2. Establish a Caregiving Hub within the New Jersey Department of Human Services that serves as a resource hub for caregivers seeking information.**
- 3. Expand availability of programs and services available to unpaid family caregivers, including respite care.**
- 4. Develop a more robust and effective paid care workforce.**

The implementation of these recommendations will take ongoing work in coordination with family caregivers, care recipients and caregiving stakeholders. With attention and dedication, caregiving in New Jersey could change from a frustrating and isolating pursuit to one whose character properly reflects its absolute necessity.

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APPENDIX A: CAREGIVER TASK FORCE LEGISLATION

CHAPTER 166

AN ACT concerning caregiver support services.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey.*

1. The Legislature finds and declares that:
 - a. An estimated 1.75 million people in New Jersey provide varying degrees of unreimbursed care to persons who are elderly or disabled and limited in their daily activities.
 - b. Caregivers are often the immediate family members of the individual being cared for, but may also be friends or community members thereof.
 - c. Although caregivers may assist an individual with the basic activities associated with daily living, including walking, eating, and dressing, they may also be expected to perform more complex daily tasks, such as administering multiple medications, providing wound care, and operating medical equipment.
 - d. The provision of care to persons with cognitive or behavioral health problems or disorders, such as persons with a mental illness, disease, or disability, can be particularly challenging, since cognitive or behavioral health issues may cause the person to resist taking medications or reject assistance with daily activities.
 - e. The act of caregiving can take a serious emotional and physical toll on the caregiver, and caregivers generally experience more physical and mental health complications, higher mortality risks, and suffer from an increased risk of depression, anxiety disorders, diminished immune response, slower wound healing, and a greater incidence of hospitalization than non-caregivers.
 - f. Many caregivers feel that they lack the necessary skill set or institutional support, or both, to perform the various tasks required of them.
 - g. Because of a lack of sufficient caregiver support services, many caregivers either miss work or are forced to quit their jobs in order to effectively provide caregiving services, and a caregiver who provides intense personal care can lose as much as \$659,000 in wages, pensions, and Social Security over the course of their caregiving career.
 - h. By 2020, the number of adults in the State who need assistance with daily living activities is expected to double.
 - i. In order to successfully address the challenges associated with the rising number of persons with significant needs for long-term services and care, and in order to ensure the provision of sufficient institutional and financial supports to the caregiver community that is engaged in the provision of essential home-based care to such persons, it is both reasonable and necessary for the Legislature to establish a caregiver task force to identify, and determine the support service needs of, caregivers in the State, and to develop recommendations for the improvement and expansion of caregiver support service programs and systems.

2.

- a. There is established the “New Jersey Caregiver Task Force.” The purpose of the task force shall be to determine the availability of caregiver support services in the State, and provide recommendations for the improvement and expansion of such services, in accordance with the provisions of this act.
- b. The Caregiver Task Force shall consist of 11 members as follows: the Commissioner of Human Services, the State Director of the New Jersey chapter of the AARP or the State Director’s designee, the Executive Director of Caregivers of New Jersey, the Executive Director of the Arc of New Jersey, the Executive Director of the National Alliance on Mental Illness New Jersey, the President of the Home Care and Hospice Association of New Jersey, the President of Leading Age New Jersey, and the President of the Alzheimer’s Association Greater New Jersey Chapter, or their designees; and three public members appointed by the Governor. The public members shall include one person who is a caregiver for a person with a disability, one person who is a caregiver for a person with mental illness, and one person who is a caregiver for an elderly person. Vacancies in the membership of the task force shall be filled in the same manner provided for the original appointments.
- c. The task force shall organize as soon as practicable, but not later than the 30th day following the appointment of its members, and upon its organization, the task force shall elect a chairperson from among its members. The task force may meet and hold hearings at the times and places it may designate, but shall hold at least one hearing in each of the northern, central, and southern regions of the State. The task force may conduct business without a quorum, but may only vote on a recommendation when a quorum is present. The members of the task force shall serve without compensation, but may be reimbursed for travel and other miscellaneous expenses incurred in the necessary performance of their duties, within the limits of funds made available to the task force for its purposes.
- d. The task force is entitled to receive assistance and services from any State, county, or municipal department, board, commission, or agency, as it may require, and as may be available to it for its purposes. The task force is further authorized to consult with any association, organization, or individual having knowledge of, or experience with, caregiver issues. The Department of Human Services shall provide professional and clerical staff to the task force, as may be necessary to effectuate the purposes of this act.
- e. The task force may solicit, receive, and expend any grant moneys or other funds that may be made available, for the task force’s purposes, by any government agency or any private for-profit or not-for-profit organization or entity.
- f. As used in this act:

“Caregiver” means any person, regardless of age, who provides assistance, in a non-medical setting, and without financial compensation, to an elderly or functionally impaired individual, by assisting the individual in the performance of their daily tasks, such as walking, eating, dressing, administering medications, providing wound care, or operating medical equipment.

- g. “Caregiver support services” means any type of support or assistance that is or may be made available to caregivers in the State, including, but not limited to, financial support or assistance from any source, and any other types of support or assistance provided by public or private employers, hospitals, health care providers or organizations, or government agencies.

2.

a. The New Jersey Caregiver Task Force, established pursuant to section 2 of this act, shall:

1. Identify, and compile an inventory of, existing State policies, resources, and programs that are available to support or assist caregivers;
2. Identify and survey caregivers in this State, in order to develop an aggregate summary of caregiver characteristics, which indicates ;
 - a. the total number of caregivers in the State;
 - b. the number of caregivers in each of the northern, central, and southern regions of the State;
 - c. the average age of caregivers;
 - d. the average time spent per week engaged in caregiving activities;
 - e. the average total period of time spent in the caregiver role;
 - f. the average amount of paid and unpaid leave time taken off work to engage in caregiving activities;
 - g. the nature and severity of illnesses or conditions suffered by the persons being cared for; and
 - h. the existing support services that are most commonly used by caregivers; and
3. Solicit and receive testimony from caregivers on the following topics:
 - a. the nature and type of simple and complex tasks undertaken by caregivers, and the frequency of caregiver engagement therein;
 - b. the feasibility of delegating certain tasks to other caregivers or to medical or non-medical personnel;
 - c. the availability and sufficiency of caregiver training programs or opportunities, and the frequency of caregiver engagement in such programs or opportunities;
 - d. the costs associated with caregiving, including, but not limited to, the loss or expenditure of caregiver income;
 - e. the availability and sufficiency of financial support services, and the frequency of caregiver use of such services;
 - f. the availability and sufficiency of respite care services, and the frequency of caregiver use of such services;

- g. the practical experiences of caregivers in relation to: (i) their requests for, or receipt of, caregiver support services; (ii) their interactions with government agencies, hospitals, health care providers and organizations, and the employees or representatives thereof, in association with caregiving matters; (iii) their interactions with public and private employers in relation to caregiving matters; and (iv) the use of medical leave for caregiving purposes; and
 - h. any other topic that is relevant to the determination of caregiver support service needs.
- b. Not later than 12 months after the task force is organized pursuant to section 2 of this act, it shall prepare and submit a report to the Governor and, pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), to the Legislature, providing its findings and recommendations in relation to the support of caregivers in the State. The report shall include, at a minimum, the following information:
 - 1. an abstract of caregiver characteristics, which summarizes information that has been obtained by the task force under paragraph (2) of subsection a. of this section ;
 - 2. a list of the caregiver support services that are currently made available from all sources, including the federal government, federal and State agencies, and public and private employers;
 - 3. a description of caregiver concerns elucidated in testimony received under paragraph (3) of subsection a. of this section; and
 - 4. recommendations for legislation, or for regulatory or programmatic changes, that would be necessary to supplement, expand, or improve the existing caregiver support services available in the State, in response to the concerns of caregivers.
- c. The task force shall dissolve 30 days after the date it submits the report required pursuant to subsection b. of this section.
- 4. This act shall take effect immediately, and shall expire on the 30th day following the submission of a task force report to the Governor and the Legislature, as provided by section 3 of this act.

Approved December 28, 2018.

APPENDIX B: BULLETED LIST OF CAREGIVER TASK FORCE RECOMMENDATIONS

Recommendation 1: Caregiver Outreach Campaign

- Recommendation: Develop an outreach and public awareness campaign
- Recommendation: Increase awareness of paid family leave benefit through the public awareness campaign

Recommendation 2: The Office of Caregiving

- Recommendation: Establish a Caregiving Hub within the New Jersey Department of Human Services that serves as a navigation resource for caregivers seeking information.
- Recommendation: Simplify available caregiver services
- Recommendation: Make it easier for caregivers to find available services
- Recommendation: Convene a caregiving stakeholder and service “network of connectivity”
- Recommendation: Identify a “caregiver program specialist” within each relevant state agency.
- Recommendation: Develop a training initiative to further develop local, public, and private caregiver support navigation services.
- Recommendation: Develop an awareness campaign to educate employers on the complex needs of caregivers.
- Recommendation: Develop and implement a statewide caregiver assessment tool.
- Recommendation: Use the New Jersey Caregiver “network of connectivity” to coordinate caregiving lessons learned from the COVID-19 pandemic

Recommendation 3: Caregiving Infrastructure Improvements

- Recommendation: Consider opportunities to provide financial relief to households that pay or incur expenses for the care and support of a care recipient.
- Recommendation: Improve programs within DHS to focus on caregivers who do not typically receive services from the State.
- Recommendation: Align eligibility requirements and services offered through State-funded home- and community-based programs which target caregivers or can assist caregivers.
- Recommendation: Expand legal service initiatives to assist caregivers in navigating the complex and often confusing legal circumstances they encounter.
- Recommendation: Increase and improve training, education and wellness programs directed at family caregivers.
- Recommendation: Improve access to technology that will assist caregivers.
- Recommendation: Improve programs that offer social support to caregivers.
- Recommendation: Increase services, particularly respite, that allow caregivers time to care for themselves.

- Recommendation: Increase the availability of high-quality, setting-appropriate, and caregiver-defined respite services to give caregivers a healthy and meaningful break from their responsibilities.
- Recommendation: Improve availability and capacity of in-home respite service providers.
- Recommendation: Increase the affordability of respite care options for caregivers.
- Recommendation: Improve the support of family caregivers during emergencies.

Recommendation 4: Care Workforce Development

- Recommendation: Recognize and recruit paid care staff
- Recommendation: Collect data on the paid care staff workforce
- Recommendation: Increase compensation for paid care staff
- Recommendation: Conduct a study on strategies for establishing rates and evaluating compensation of paid care staff.
- Recommendation: Train paid care staff on key competencies that improve care of the recipient and ease the worry of caregivers.

APPENDIX C: MEMBER BIOGRAPHIES

Louise Rush, Division Director, New Jersey Division of Aging Services

In her role as Director of the Division of Aging Services (DoAS), Louise Rush manages a staff of approximately 300 people and a budget of about \$330 million to administer a variety of state and federal programs, services, and supports that are designed to maximize the independence of New Jersey's aged population as well as to protect its most vulnerable seniors. Throughout her entire career of over 40 years with the State of New Jersey, her passion has been ensuring that seniors and the disabled have access to the services and programs they need to remain in their own communities with loved ones and friends and to avoid placement in a nursing facility for as long as possible.

609 438-4554 | doas@dhs.nj.gov | aging.nj.gov | adrcnj.org

Nancy Fitterer, President & CEO, Home Care & Hospice Association of New Jersey

Nancy Fitterer is the President & CEO of the Home Care & Hospice Association of NJ. The Association represents Medicare certified home health agencies, hospices and health care service firms. The Association's mission is to inform, educate, assist and advocate for home care and hospice providers and the patients and families they serve throughout New Jersey. Prior to joining the Association, Nancy served as Chief of Staff to two New Jersey Attorneys General. Nancy also served in various other capacities during her eight-year tenure in the Office of the Attorney General, including Chief of Staff of the Division of Consumer Affairs. She is a graduate of both The College of New Jersey with a B.A. in political science and Seton Hall University with an M.A. in international relations and diplomacy.

732-877-1100 | homecarenj.org

Celine Fortin, MSW, LSW, Associate Executive Director, The Arc of New Jersey

Céline Fortin has played several roles with The Arc for more than 30 years, focused on advocacy and support for children and adults with intellectual and developmental disabilities and their families. She is also the caregiver of an adult child with Autism and mental health conditions.

732-246-2525, ext 38 | info@arcnj.org | arcnj.org

Brandon Eldershaw, LeadingAge New Jersey

Brandon Eldershaw develops and coordinates wellness programs to meet the needs of the Aging population, including specialized educational services that focus on the caregiver population.

609-452-1161 | leadingagenjide.org | info@leadingagenjide.org | 732-308-0570
centrastate.com | wellness@centrastate.com

Meredith Masin Blount, Executive Director, NAMI NJ

Meredith Masin Blount is the Executive Director of NAMI NJ, a leading voice on mental illness in New Jersey. NAMI New Jersey (NAMI NJ) is a statewide nonprofit organization dedicated to improving the lives of individuals and families affected by mental illness. NAMI NJ, in conjunction with its 19 affiliates across the state, held more than 600 support groups, 310 education classes and provided more than 260 presentations in 2019. Prior to NAMI NJ, Ms. Blount was the Senior Director of Youth Services for New Brunswick Tomorrow. Through this role, Ms. Blount managed the state's largest School Based Youth Services Program – providing mental health counseling and youth development services to students in New Brunswick Schools. The program had steadily grown over her seven-year tenure and expanded to seven schools, serving more than 1,000 New Brunswick students yearly. Prior to joining New Brunswick Tomorrow, Ms. Blount worked at the New Brunswick Housing Authority; creating the Social Services Department within the agency. She also was an AmeriCorps*VISTA Volunteer with the Massachusetts Housing and Shelter Alliance in Boston. Meredith is also a proud wife to a very patient husband and mother to 3 soccer boys: 15, 12, 7. If you do not see her in the office, you can probably hear her cheering on the soccer fields every weekend. Every weekend.

732-940-0991 | info@naminj.org | naminj.org

Liza Gundell, Chief Executive Officer, Caregivers of New Jersey

Liza Gundell is the Chief Executive Officer of The Family Resource Network and its affiliate organizations Autism Family Services of NJ; Caregivers of NJ and Epilepsy Services of NJ. The Network provides services and supports to people of all ages with intellectual and developmental disabilities and chronic illnesses and their caregivers. She has worked for the organization for 27 years. Liza is also the primary caregiver for her mother who just turned 90 and lives with her.

800-372-6510 | www.familyresourcenetwork.org | njcaregivers.org

Crystal McDonald, Associate State Director of Advocacy, AARP New Jersey

Crystal McDonald is the Associate State Director of Advocacy for AARP New Jersey where she helps to plan and execute campaigns to support family caregivers, improve health care access and affordability, promote retirement security and ensure access to affordable utilities. Crystal brings over ten years of experience in community organizing, health policy, and coalition building. Prior to her role at AARP, she worked on Medicaid policy and advocacy for NJ Health Care Quality Institute, Faith in New Jersey, and NJ Citizen Action. She is a graduate of the Richard Stockton College of New Jersey.

866-542-8165 | aarpnj@aarp.org | aarp.org/nj

Cheryl Ricci- Francione, Executive Director, Alzheimer's Association of Greater New Jersey

Cheryl Ricci-Francione has served as the Executive Director of the Alzheimer's Association's Greater New Jersey Chapter since 2017. She has been a nonprofit business professional for over 20 years. She is a graduate of Rutgers University, and holds a Master of Science degree in Human Services and Not for Profit Executive Management and Leadership from Springfield College. She is committed to providing resources and support to dementia caregivers. Her focus is on inclusion, equity and access for all residents of New Jersey, especially our older adult population.

800-272-3900 | alz.org/nj

Susan McAndrews, Caregiver to an individual with mental illness

Susan McAndrews has extensive personal experience caring for both of her parents at the end of their lives, as well as the ongoing responsibility for her disabled sibling. Over the last 15 years, Susan and her family have utilized almost every aspect of home care available. They started with Home Helpers and progressed to 24 hour live-in Home Health Aides and, eventually, Hospice Care. Susan managed the groceries, the medications, the doctor's visits and unfortunately, visits to the hospital and Emergency Department. Susan has experienced the challenges of paying for care ...the bills, the inaccurate billing, the insurance, and the cash outlays. She appreciates how challenging and stressful it can be to deal with the many different agencies, insurance companies, pharmacies, physicians and therapists that are involved in the care of just one person. She understands how difficult it can be for caregivers to maintain their own health, meet the obligations of their families and maintain their employment in the midst of caring for a family member whose illness requires Home Health Care. Susan is currently Program Developer and Clinical Nurse Educator for Bayada Home Health Care. She is responsible for orienting and training nurses new to Bayada in the skills, knowledge and attitudes that are needed to be successful in the care of clients with chronic illness and their families.

Kathleen Lolla, Caregiver to an individual with intellectual and developmental disabilities

Kathleen Lolla is a dentist, a mother of four and full-time caregiver for her adult son with Intellectual and Developmental Disabilities. Given her 27 years as caregiver to her special needs son, as well as having a parent with Alzheimer's and Parkinson's, she is uniquely qualified for the task force. In light of her particular experience, Kathleen possesses the ability to both address and illuminate the distinct challenges of caregivers.

APPENDIX D: CAREGIVER TASK FORCE SURVEY

The New Jersey Caregiver Task Force was created by the Murphy Administration and the Legislature to shape recommendations on expanding and enhancing support services for caregivers.

This survey is an important part of that process.

Caregivers have powerful insight and stories, and the New Jersey Caregiver Task Force wants to hear you. Your direct feedback through this survey will help us better understand the caregiver experience and help identify caregiver needs.

This survey is being conducted by the Task Force in conjunction with the New Jersey Department of Human Services. For further information about the Task Force please visit the Caregiver Task Force webpage.

For the purpose of this survey, a caregiver means any person, regardless of age, who provides assistance to a relative, partner, friend, or neighbor in the performance of daily tasks such as walking, eating, dressing, errands, medication, wound care, operating medical equipment, etc.

The caregiving occurs in a non-medical setting, such as a home, and with little or no financial compensation. The person receiving care can be an older adult or individual with mental health challenges, physical disabilities, chronic health conditions, cognitive or behavioral health challenges or intellectual and developmental disabilities.

The survey should take about 10 to 20 minutes to complete. We ask that you complete as much of the survey as possible, though if you are unable or choose not to complete the entire survey the responses you give will still be included in our results if you submit the survey.

Your participation in this survey is voluntary and will not affect any services you receive. All responses are anonymous, unless you choose to provide contact information at the end of the survey. If so, your personal and identifying information will not be reported with the results.

At the end of the survey you will be able to share with the New Jersey Caregiver Task Force any additional information or concerns about your caregiving experience. The Task Force will also provide other opportunities for participation in this process, such as virtual listening sessions scheduled for March 6t, 10th and 18th 2021. Visit the Caregiver Task Force webpage for more information.

Any questions regarding this survey can be sent to doas.caregivertaskforce@dhs.nj.gov.

Thank you for your consideration.

- 1. Which county do you live in?**
- 2. What is your age group?**
- 3. What is the age group of the care recipient (individual you provide care for)?**
- 4. Are you of Hispanic, Latino, or Spanish origin? (choose all that apply)**
 - No, not of Hispanic, Latino, or Spanish origin
 - Yes, Cuban
 - Yes, Mexican, Mexican American, Chicano
 - Yes, Puerto Rican

- Yes, another Hispanic, Latino, or Spanish origin (For example, Argentinian, Colombian,
- Dominican, Nicaraguan, Salvadorian, Spaniard, etc.)
- Choose not to answer

5. What is your race? (Choose all that apply)

- White
- Black or African American
- American Indian or Alaska Native
- Asian Indian
- Native Hawaiian
- Chinese
- Japanese
- Samoan
- Filipino
- Vietnamese
- Guamanian or Chamorro
- Korean
- Other Asian (For example, Hmong, Laotian, Thai, Pakistani, Cambodian, etc.)
- Other Pacific Islander (For example, Fijian, Tongan, etc.)
- Choose not to answer
- Some other race (Please list here)

6. What is your primary language?

- a. How well do you speak English?
- Very well
 - Well
 - Not Well
 - Not at all

7. Who do you care for?

- Spouse/Partner/
- Parent/in-laws
- Child (Under 21)
- Adult Child (over 21)
- Grandparent
- Grandchild

- Other Relative
- Girl/Boyfriend
- Neighbor/Friend
- Other (please specify)
- Significant Other

8. What is the impairment that requires you to provide care for the care recipient?(Check all that apply)

- Chronic Illness/Health Condition(s)
- Physical Disability
- Intellectual/Developmental Disability
- Mental Illness
- Older adult (65 years or older)
- Memory/Cognitive Impairment (dementia, Alzheimer's, TBI, MCI, stroke)
- Sensory Disability (deafness/hearing loss, visual impairment/low vision)
- Long term impacts of COVID19
- Don't Know/Prefer not to answer
- Other (please specify)

9. Are you a caregiver for more than one person?

- Yes
- No

10. If yes, please describe the relationship of the caregiving (for example, the relationship you have to each care recipient and the impairments that require you to provide care).

11. Are you the parent/guardian of any children under 21?

- Yes
- No

12. Has your living situation changed due to caregiving? (for example: moved in with care recipient, care recipient moved in with me,renovations necessary for care recipient, etc.)

- Yes
- No
- Don't Know/Prefer not to answer

13. How long have you provided care for the care recipient?

- Less than 30 days
- One month to less than six months

- Six months to less than one year
- One year to less than two years
- Two years to less than five years
- Five years or more
- Don't Know/Unsure
- Other (please specify)

14. What was your total household income before taxes during the past 12 months?

- Under \$15,000
- \$15,000 and \$29,999
- \$30,000 and \$49,999
- \$50,000 and \$74,999
- \$75,000 and \$99,999
- \$100,000 and \$150,000
- Over \$150,000
- Don't Know/Prefer not to answer

15. What is your employment status? (select all that apply)

- Employed Full-time (35-40 hours a week)
- Employed Part-time (34 hours or less)
- Self-employed
- Not Employed (job searching)
- Not Employed (stay at home by choice)
- Retired
- Student
- Don't Know/Prefer not to answer
- Other (please specify)

16. How much does caregiving interfere with your ability to maintain or start a job outside the home?

- A great deal
- A lot
- A moderate amount
- A little
- None at all

17. How supportive is your employer in regards to your caregiving activities?(select all that apply)

- Allows to flex work hours
- Allows to use leave time as needed and is accommodating to schedule
- Allows to use leave time when schedule allows
- Allows to use most leave time but not accommodating to schedule
- Unable to use leave time
- Other (please specify)

18. Have you lost pay due to missing work for caregiving activities?

- Yes
- No
- Don't Work
- Don't Know/Prefer not to answer

19. How would you rate your ability to find resources for your caregiving needs?

- Very Easy, Resources are easy to find and readily available
- Very Difficult, Resources are difficult to find and access

20. Are there any accommodations or adaptations that would make caregiving resources easier to understand? (Select all that apply).

- Language Translation/ Interpretation
- Hearing Loss or Deafness (such as sign language translation interpretation, captioning, etc.)
- Low-vision or Blind (such as larger print, screen reader accessible, etc.)
- No Accommodations or Adaptations
- Other (please specify)

21. How would you classify your caregiver duties?

- Continuous (24 hours a day, 7 days per week)
- Full-time (35-40 hours per week)
- Part-time (16-30 hours per week)
- 15 hours or less per week
- Occasional (as needed basis)
- Don't know/prefer not to answer

22. Do you help your care recipient to do any of the following activities? (Check all that apply)

- Ambulation/Transferring (walking/moving in and out of chair, or bed, or toilet, etc.)
- Grooming, Bathing, Dressing/Changing Clothes

- Toileting
- Feeding (assistance to eat or drink)
- Cooking and Food Preparation, Help with Meals
- Household chores (laundry, housekeeping, etc.)
- Housekeeping (sweeping, vacuuming, dishes, etc.)
- Shopping (taking them or shopping for them; including grocery shopping)
- Money/Financial Management (bill paying)
- Residential Maintenance (indoor or outdoor)
- Transportation (appointments, personal errands, social events)
- Companion Services, Friendly Visiting
- Participating in community activities (going to the movies, eating at a restaurant, visiting a museum, etc.)
- Assistance on a job site (prompting to continue attending to tasks, personal care, ensuring the individual stays on the job site, assistance with breaks/lunch, etc.)
- Care Coordination (talking with providers, arranging care)
- Medication Management (refilling prescriptions, talking with physicians, filling pillbox, administering/giving medications)
- Physical Therapy/Occupational Therapy Exercises
- "Nursing-type" or "skilled" Care (hands on tasks like injections, wound care, G-tube or other artificial feeding, breathing treatments, specialized skin care, braces, oxygen management, catheter care, ostomy care, etc.)
- Other (please specify)
- Language Translation/Interpretation

23. Are you compensated in any way for the care that you provide? (privately, Personal Preference Program (PPP) or other self directed program, Participant Employed Provider (PEP), Aid and Attendance etc.)

- Yes
- No
- Don't Know/Prefer not to answer
- Other (please specify)

24. If you are compensated for the care you provide, what percentage of your time spent caregiving is paid? 0% 50% 100%

25. In the past year, have you spent your personal funds on items related to caregiving (like assistive devices, medication, home care, clothing, travel, activity expenses etc.)

- Yes
- No

- Don't Know/Prefer not to answer

26. If so, please try to estimate how much?

27. Are there medications, supplies, care or treatments that the care recipient should have, but cannot afford?

- Yes
- No
- Don't Know/Unsure

28. If yes, what types of medications, supplies, care or treatments are they?

29. Please check all of the situations below that you have experienced.

- Found it difficult to take care of your own household
- Found it difficult to take care of your own health
- Found it difficult to maintain personal relationships and/or personal activities
- Found it difficult to take care of your family, spouse, children, etc.?
- Had to reduce personal savings
- Had to ask others for financial help
- Go into work early or late, or take time off to provide care for a loved one
- Take a leave of absence from your job to provide care for a loved one
- Go from working full-time to part-time to provide care for a loved one
- Give up working entirely to provide care for a loved one
- None of the above
- Don't Know/Prefer not to answer

30. Does your care recipient receive financial support from a program that contributes toward the cost of caregiving (such as Jersey Assistance for Community Caregiving (JACC)/Medicaid Managed Long Term Services and Supports (MLTSS)/etc.)?

- Yes
- No
- Don't Know/Prefer not to answer
- Other (please specify)

31. Do you utilize the following services/programs?

	Yes, we use this service	No, we don't use this service	I want more information on this service
Assistive Technology/Devices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behavioral Support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interpreter Services (ASL and spoken language)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employment Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emergency support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prescription Assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical supplies and equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Durable Medical Equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Therapies (Occupational, Physical, Cognitive, Speech)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Training for specialized care tasks you assume	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Visiting Nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nursing care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paid live-in help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Private duty nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal Care Assistant/Home Health Aide	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Companion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in community or recreational activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respite care (short-term relief/break from caregiving)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

32. Based on the question above, is there any information you would like to share about your experiences with these services? (Examples: I have a hard time finding a visiting nurse in my area; I applied for prescription assistance but was denied; I have never heard of behavioral support but it sounds like something I could use; etc.)

33. If I could, I would....

- Share my responsibilities with professional service providers
- Share my responsibilities with other family members
- Consider moving care recipient to a long-term care facility (nursing home, assisted living facility, other residential placement)
- Reduce significantly my care responsibilities but remain involved
- Have someone else take over all of my responsibility as a caregiver
- Discontinue my involvement in the care recipient's care
- Continue as caregiver with no changes
- Don't Know/Prefer not to answer

34. How would you rate your stress as a caregiver? (10 being the most stressed, 1 being the least)

35. What would you say is the most stressful aspect of being a caregiver?

36. What kinds of alternative supports would make your role as a caregiver easier or assist with care to your loved one?

- a. Is immigration status a barrier to access support services for the care recipient? If yes, please share more information on how it acts as a barrier.

37. Would you change anything about your current caregiving situation?

38. Has COVID-19 impacted your caregiving situation? Are there additional supports needed due to the COVID-19 pandemic?

39. Is there anything else you'd like to share about your experiences as a caregiver? Is there anything you would like to share that we have not asked?

40. If you would like to be contacted for assistance with accessing caregiver services, please leave your information below.

Name	
Nature of your request	
County	
Email Address	
Phone Number	

Caregiver Task Force, Draft 2/25/21 Caregiver Characteristic Survey

Resources from the Department of Human Services

- Affording Health Care Coverage: Visit www.NJFamilyCare.org
- Affording Groceries: Visit www.NJSNAP.gov
- Income Assistance for Individuals and Families: Visit NJHelps.org
- Child Care, Including for your School-Age Children Learning Remotely: Visit www.ChildCareNJ.gov
- Addiction Treatment and Recovery: Call 844-REACHNJ
- Mental Health & Emotional Support: Call 866-202-HELP or 973-870-0677
- Supports for Older Residents: Call 877-222-3737
- Services for Individuals with Disabilities: Call 888-285-3036

APPENDIX E: SURVEY RESULTS

Caregiver Task Force Survey

New Jersey
Department of Human Services
Division of Aging Services

Survey Statistics

- 907 responses were collected from May 3, 2021 through July 2, 2021 (61 days)
- Survey is 9.6 Flesch-Kincaid Grade Level

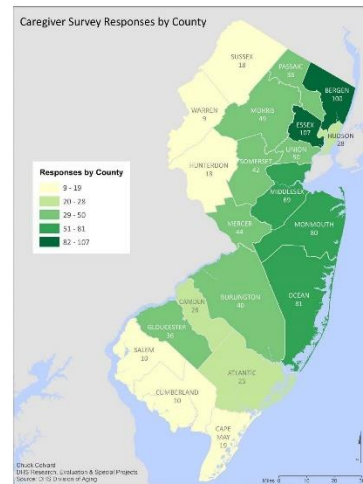
Limitations

- Sample is likely skewed due to the fact that people already connected to community based advocacy organizations are more likely to respond to the survey
 - Could skew towards more retired, higher income and more connected individuals
 - Survey is between 9th and 10th grade level literacy in English so the sample probably didn't capture caregivers with lower English fluency and literacy

How has the COVID-19 pandemic impacted caregivers? Keep this in mind as the survey was distributed during the second summer of the pandemic.

Characteristics of caregivers

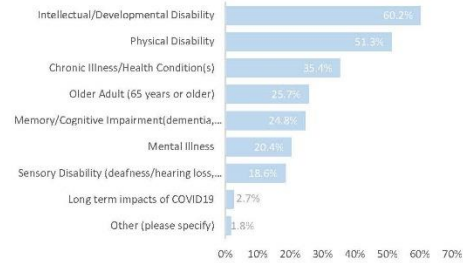
- Bergen and Essex were the most common counties
- Most common age range was 56-65 (39.6%)
- 10.4% were Hispanic, Latino or Spanish origin
- 79.5% White, 8.9% Black
- 1.2% speak English less than very well (12.1% of NJ residents over age 5 speak English less than very well, 2019 5-year ACS)
- More than half (55.9%) were employed (full-time, part-time or self-employed), 32.4% retired
- 43.0% cared for parents/in-laws and 26.4% cared for their spouse/partner/significant other
- About 1 in 5 parent/guardian of a child under 21



Characteristics of caregivers (cont.)

- Average rating for ability to find resources was 66.6 and median was 73 (0=very easy, 100=very difficult)
- 82.2% are not compensated, 12.6% are compensated. Of the compensated, 45% are compensated for less than 30% of time spent. 11.9% are paid for 100% of the time spent

Impairment type of those compensated:

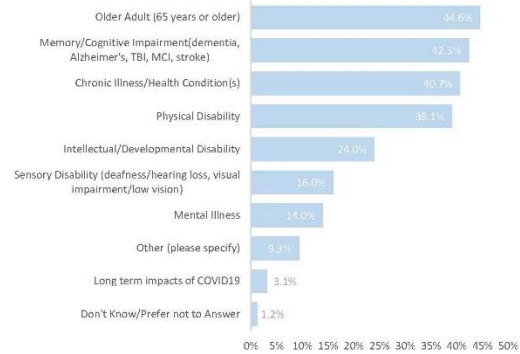


Note: Percentages sum to greater than 100 because respondents can check more than one

Characteristics of care recipient

- Almost three-quarters (71.1%) were between 66 and 95 years old.
- 61.5% identified 2 or more impairments that required care
- Almost 20% indicated that there are medications, supplies, care or treatments that they should have but can't afford. Top 3 were:
 - prescriptions not covered or partially covered by insurance
 - medical, incontinence and other supplies
 - home health aides
- 73.7% care recipients do not receive financial support to cover the cost of caregiving

What is the impairment that requires you to provide care for the care recipient? (n=900)



Note: Percentages sum to greater than 100 because respondents can check more than one

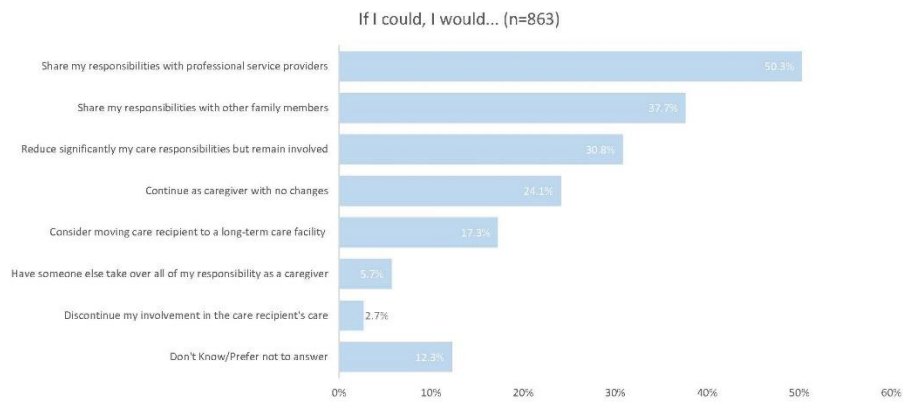
Characteristics of care recipient (cont.)

- Top 5 utilized services:
 - Medical supplies & equipment (31.7%)
 - Lawn service/snow removal (31.0%)
 - Equipment therapies (26.4%)
 - Prescription assistance (25.9%)
 - Visiting nurse (24.8%)
- 5 least commonly utilized services:
 - Interpreter services (1.4%)
 - Assistance on a job site (3.8%)
 - Employment Services (3.8%)
 - Private duty nurse (4.2%)
 - Vehicle modification (4.4%)

11.1%

have utilized respite care

Caregiver preferences



Note: Percentages sum to greater than 100 because respondents can check more than one

Measuring and defining caregiving

- Top 5 activities:
 - shopping (85.7%)
 - transportation (84.6%)
 - cooking and food preparation, help with meals (83.6%)
 - household chores (83.0%)
 - housekeeping (80.3%)
- 5 least common activities:
 - Physical Therapy/Occupational Therapy exercises (28.3%)
 - “nursing type” or “skilled” care (20.8%)
 - language translation/interpretation (11.0%)
 - other (9.6%)
 - assistance on a job site (5.5%)

1 in 4

(24.3%) care for *more than one individual*

More than half

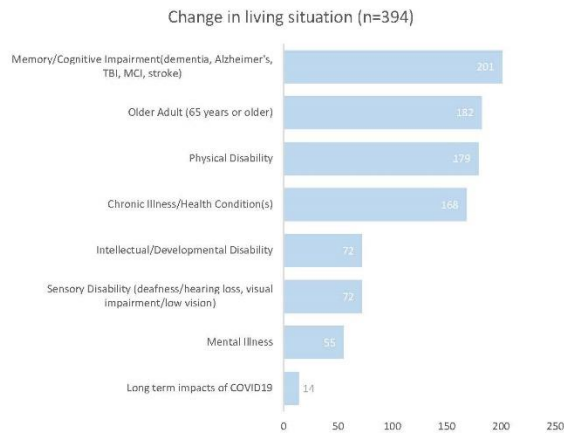
(51.0%) work *continuously* as a caregiver

More than half

(53.4%) have provided care for *5 years or more*

Impacts of caregiving

- About 44% indicated their living situation changed due to caregiving
- 81.8% indicated that caregiving interfered a little or more with their ability to maintain or start a job outside of the home

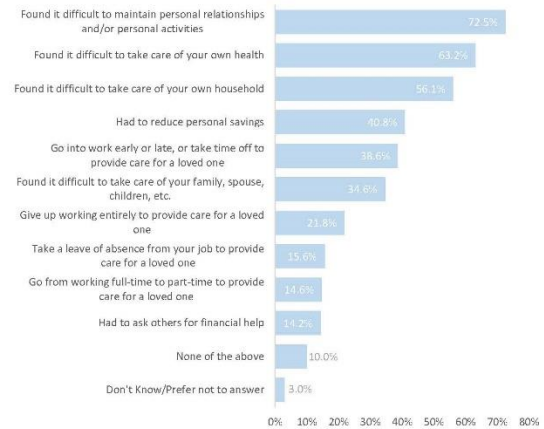


Note: Percentages sum to greater than 394 because respondents can check more than one

Impacts of caregiving

- 5.6% of respondents indicated that their employer does not allow them to use leave time
- 29.0% lost pay due to caregiving
- Over 70% have spent personal funds on items related to caregiving
- Of those who spent personal funds, the average amount was \$6,297.38 per year. The median spending was \$2,000 per year.

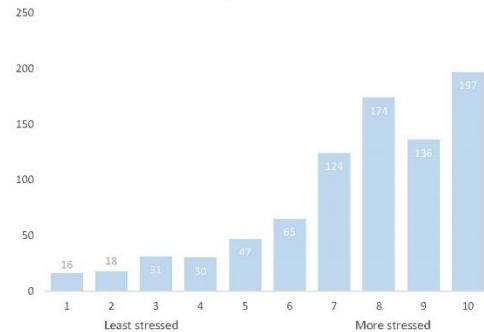
Please check all of the situations below that you have experienced (n=899)



Impacts of caregiving

- 60.5% of respondents rated their stress levels between 8 and 10.
- Average of 7.57 and median was 8

How would you rate your stress as a caregiver? (n=838)

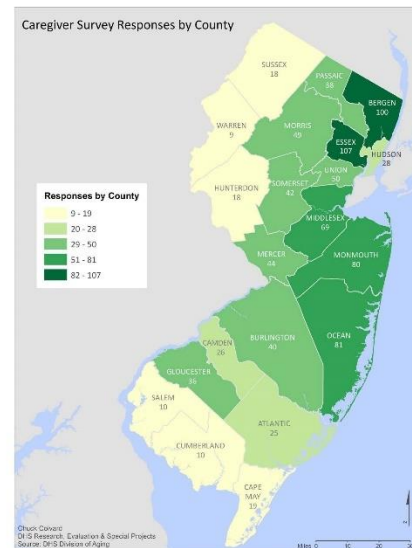


Characteristics of caregivers

- County
- Age
- Race
- Language spoken
- Income
- Employment status
- Relation
- Compensation

County

Most caregivers who responded to the survey were from Bergen County and Essex County. There were fewer than 20 responses from Cape May, Sussex, Hunterdon, Cumberland, Salem and Warren counties.

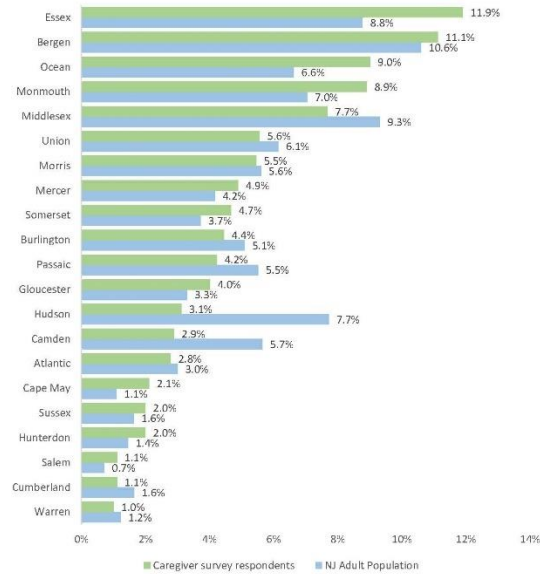


County

There was a higher share of responses to the caregiver survey than the share of the NJ general population in Essex, Bergen, Ocean, Monmouth, Mercer, Somerset, Gloucester, Cape May, Sussex and Salem Counties.

There was a smaller share of responses to the caregiver survey than the share of the NJ general population in Middlesex, Union, Morris, Burlington, Passaic, Hudson, Camden, Atlantic, Cumberland and Warren counties.

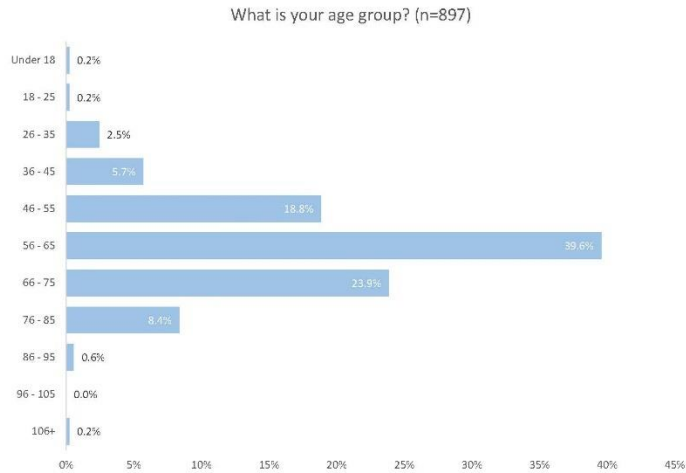
It is unclear if these differences identify counties that were not represented enough in survey responses or if there is a true difference in the concentration of caregivers across counties.



Source: American Community Survey 2019 1-year estimates Table S0101 Age and Sex

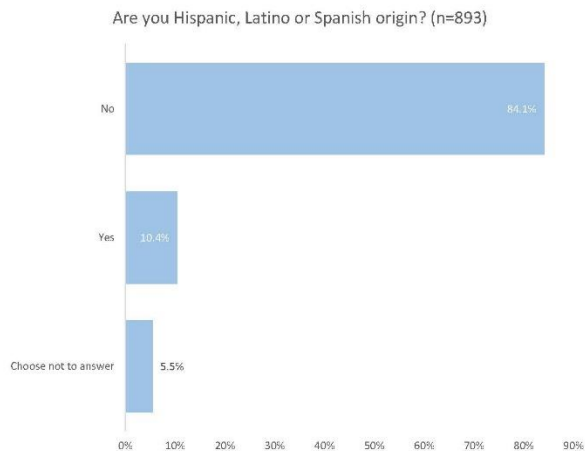
Age

The most common age group was between 56 and 65 with 355 respondents or 39.6% of respondents. Age groups of 66 to 75 and 46 to 55 were second and third most common with 23.9% and 18.8% respectively. 82.3% of the respondents were between the ages of 46 and 75.



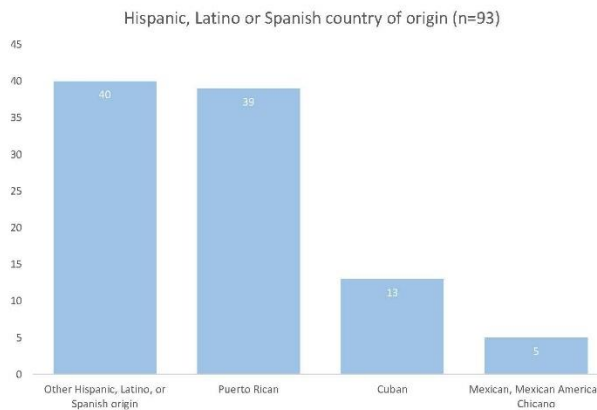
Origin

10.4% of caregivers who responded to the survey were of Hispanic, Latino or Spanish origin.



Country of origin if Hispanic, Latino or Spanish

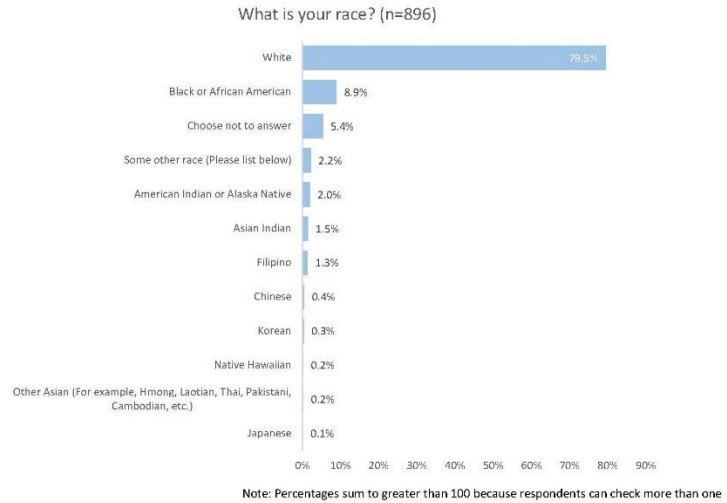
Of the 93 respondents who identified as Hispanic, Latino or Spanish, 40, or 43% identified as other Hispanic, Latino or Spanish origin. 39 or 41.9% identified as Puerto Rican and 13 or 14.0% Cuban. Another 5 respondents, or 5.4% identified as Mexican or Mexican American.



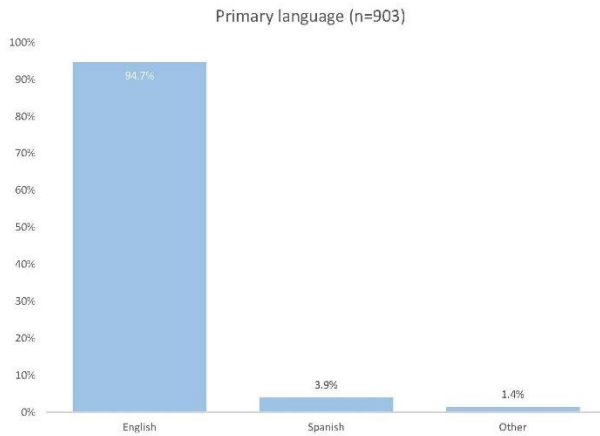
Note: Sums to greater than 93 because respondents can check more than one

Race

79.5% of respondents identified as White, 8.9% were Black or African American and 5.4% chose not to answer.



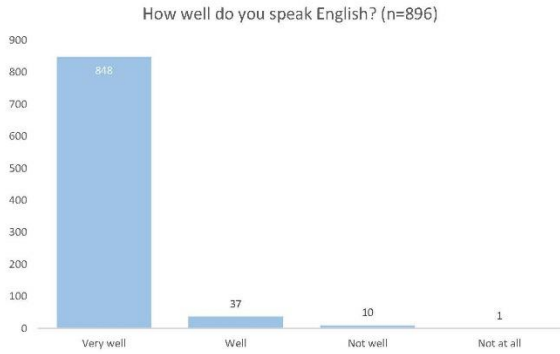
Primary language



The majority, or 94.7% of respondents identified English as their primary language. 3.9%, or 35 identified Spanish as their primary language. Another 1.4% identified other languages including 4 Gujarati (0.4%), 2 Italian (0.2%), 2 Russian (0.2%), 2 Korean (0.2%), 1 Portuguese (0.1%), 1 Arabic (0.1%) and 1 Tagalog (0.1%).

In NJ, 31.3% of people over the age of 5 speak a language other than English at home according to the American Community Survey 2019 5-Year estimates. Only 5.3% of the respondents indicated their primary language is not English.

English fluency



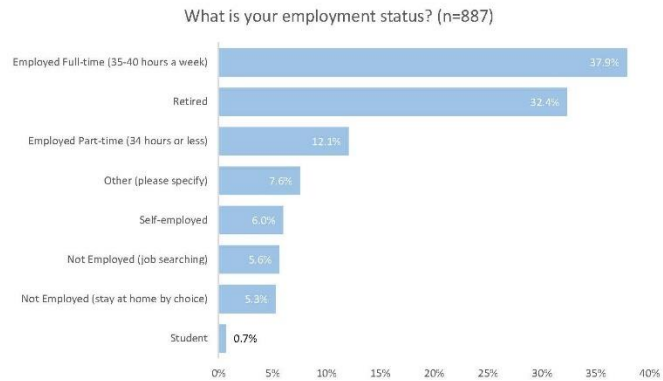
Most respondents, 94.6% speak English very well. 37 or 4.1% speak English well while 11 or 1.2% speak English not well or not at all.

About 12.1% of New Jersey residents over the age of 5 speak English less than very well when they speak a language other than English at home according to the American Community Survey 2019 5-year estimate. Only 5.4% of the caregivers who responded to the survey indicated that they speak English less than very well.

Employment status

20 out of 907 (2.2%) respondents did not provide their employment status, preferred not to answer/don't know or left the question blank. Of the 887 respondents that answered the question about their employment status 37.9% indicated that they work full time. The second most common employment status is retired with 32.4% of caregivers. Students were the least common with less than 1% of the responses.

More than half (55.9%) of caregivers surveyed work full-time, part-time or self-employed. 15 caregivers or 1.7% identified two or more jobs including self-employed, full-time, part time or student.



Note: Percentages sum to greater than 100 because respondents can check more than one

Employment status and age

Caregiver age by Employment status	Employed Full-time	Employed Part-time	Self-employed	Not employed (job searching)	Not employed (stay at home by choice)	Retired	Student	Other	Don't Know/Prefer not to answer
Under 18	2	1	0	0	0	0	0	0	0
18-25	0	2	0	0	0	0	0	0	0
26-35	10	3	3	4	2	0	0	2	1
36-45	33	6	2	3	5	1	2	5	0
46-55	104	27	11	12	6	5	3	13	2
56-65	154	46	25	25	25	52	1	36	11
66-75	24	16	9	5	7	153	0	10	2
76-85	4	3	0	1	2	66	0	1	0
86-95	1	1	0	0	0	3	0	0	0
95-105	0	0	0	0	0	0	0	0	0
106+	1	0	0	0	0	1	0	0	0

Income

The most common income bracket was \$50,000 to \$74,000 with 20.7% of all responses. 17.5% of all responses made \$29,999 or less a year.

According to the American Community Survey 2019 1-year estimates, **29.2%** of New Jersey households made less than \$50,000 a year while **30.8%** of respondents reported a household income of less than \$50,000.

What was your total household income before taxes during the past 12 months? (n=701)



Household income and employment status

Household Income by employment status	Under \$15,000	\$15,000 & \$29,999	\$30,000 & 49,999	\$50,000 & \$74,999	\$75,000 & \$99,999	\$100,000 & 150,000	Over \$150,000
Employed Full-time	5	13	27	60	61	67	32
Employed Part-time	5	17	10	14	12	18	8
Self-employed	3	7	3	5	11	8	5
Not employed (job searching)	5	11	7	4	7	3	1
Not employed (stay at home by choice)	3	7	4	6	2	3	3
Retired	7	31	38	52	38	44	11
Student	4	0	0	0	0	0	1

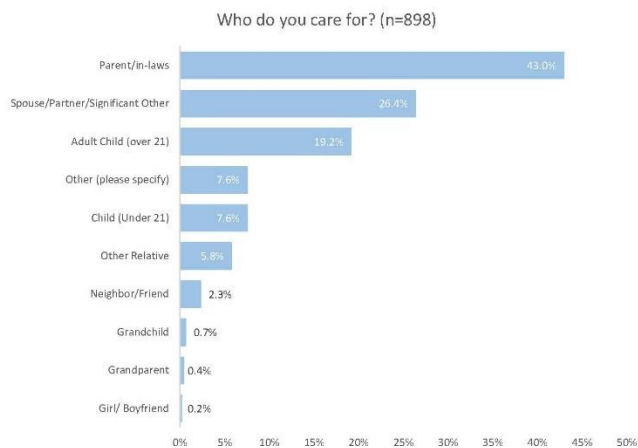
Household income and age

Household Income by caregiver age	Under \$15,000	\$15,000 & \$29,999	\$30,000 & 49,999	\$50,000 & \$74,999	\$75,000 & \$99,999	\$100,000 & 150,000	Over \$150,000	Don't Know/Prefer not to answer
Under 18	0	0	0	0	0	0	2	0
18-25	1	0	0	0	0	0	0	1
26-35	3	3	4	2	1	3	1	5
36-45	4	7	3	6	11	8	6	6
46-55	9	4	11	30	24	30	16	45
56-65	11	35	36	51	62	56	29	75
66-75	4	28	28	34	33	32	3	50
76-85	3	6	9	20	6	8	4	17
86-95	1	0	1	0	0	2	0	1
95-105	0	0	0	0	0	0	0	0
106+	0	0	0	1	0	1	0	0

Relation

Respondents most often cared for their parents or in-laws (43.0%) and their spouse, partner or significant other (26.4%). Another 19.2% cared for their adult children and 7.6% for their children under 21 years old. Respondents were caring for a neighbor or friend for 2.3% of cases.

The least common relation to the individual receiving care was girlfriend or boyfriend (0.2%), grandparent (0.4%), and grandchild (0.7%).



Note: Percentages sum to greater than 100 because respondents can check more than one

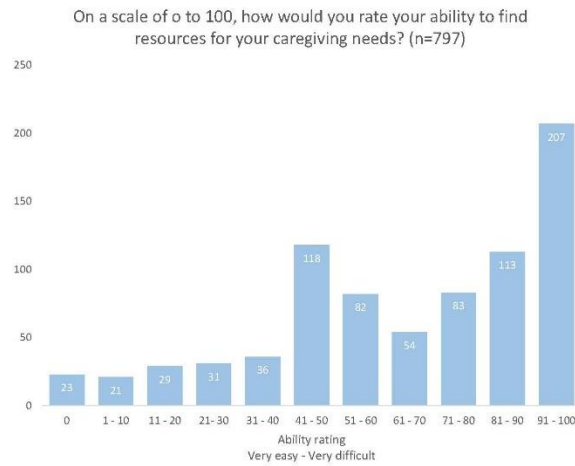
Are you the parent/guardian of any children under 21?



About one in five caregivers indicated that they are the parent/guardian of a child under 21

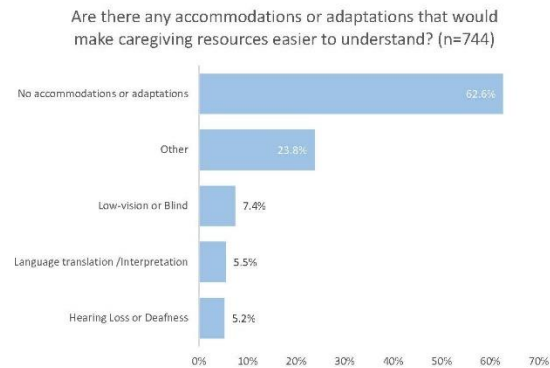
Ability to find resources

The average rating for ability to find resources for caregiving needs was 66.6 and the median rating was 73. The most common ranges of ratings were between 91 and 100 (26.0%). The least common ranges of ratings was between 1 and 10 (2.6%).



Resource adaptations

When asked what accommodations or adaptations would make caregiving resources easier to understand, no accommodations or adaptations (62.6%) were the most common response. Other accommodations (23.8%) were the second most common which revealed many suggestions. Of the three accommodations listed, low-vision or Blind (7.4%) was the most common. Language translation/ interpretation (5.5%) and Hearing Loss or Deafness (5.2%) were the second and third most common.

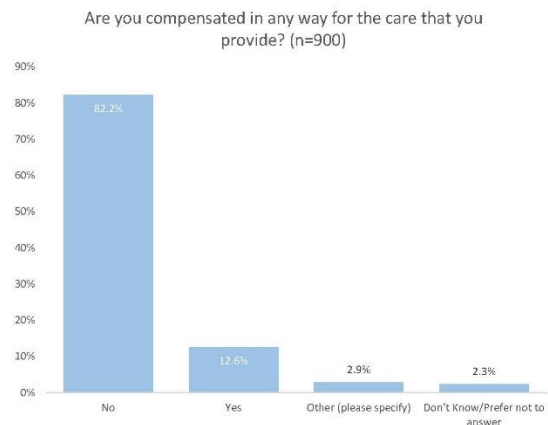


Resource adaptations (continued)

- Other accommodation themes:
 - Invalid responses, misunderstanding the question, responding with resources that are needed instead of what is needed to access available resources (n=88)
 - Perceptions that there are no resources available (n=5)
 - Resources organized by location or county
 - Simpler language/literacy
 - HIPAA laws creating obstacles
 - Agencies to help connect to resources
 - Extended business hours to accommodate work schedules
 - Transportation, issues with AccessLink
 - Education, training & workshops for caregivers about resources and LTC options
 - Less paperwork
 - Website resources, monthly mailed bulletin, material dissemination
 - Centralized information source, one-stop agency, live help
 - Sensory adaptations

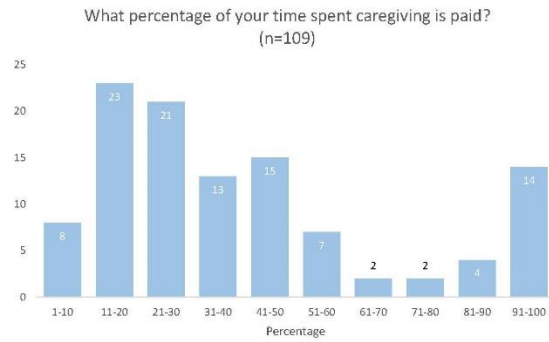
Compensation

Most (82.2%) caregivers are not compensated for the care they provide. Only 113, or 12.6% out of 900 respondents reported that they are compensated for being a caregiver.

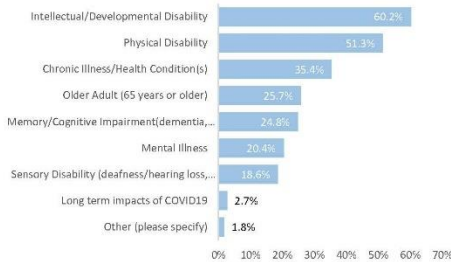


Compensation (continued)

Of those who indicated that they are compensated for caregiving, more than 45% of the respondents are compensated for less than 30% of the time spent caregiving. Only 11.9% or 13 individuals who are paid for caregiving are paid for 100% of the time spent caregiving.



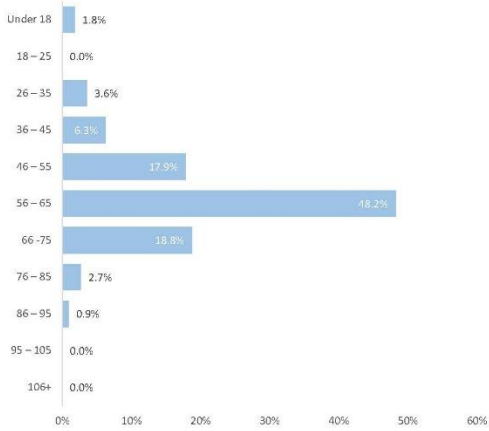
Compensation by impairment type



Note: Percentages sum to greater than 100 because respondents can check more than one

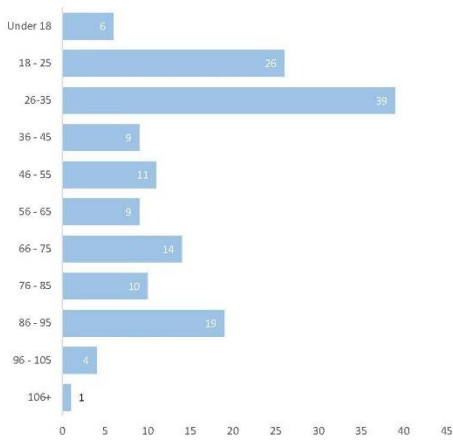
- Of the 113 caregivers who indicated that they are compensated in any way, 60.2% were caring for an individual with an intellectual/developmental disability. Another 51.3% indicated they cared for an individual with a physical disability followed by chronic illness/health condition(s) with 35.4% of the compensated caregivers.

Compensation by caregiver age



Of the 112 caregivers who indicated that they are compensated in any way and provided their age, 48.2% between 56 and 65 years old. Another 18.8% indicated they were between 66 and 75 years old followed by 46 and 55 years old with 17.9% of the compensated caregivers.

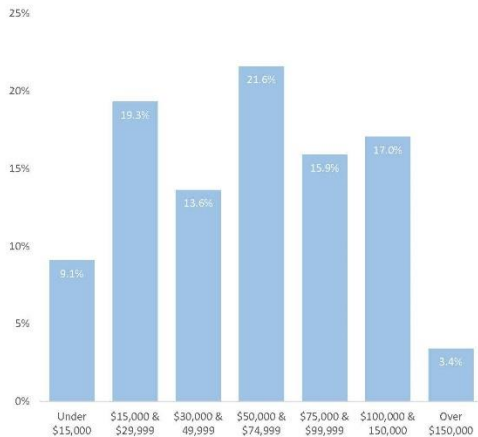
Compensated by Care Recipient Age



Caregivers who indicated that they are compensated for caregiving are most often caring for an individual between the ages of 26 and 35 years old and 18 and 25 years old.

Note: Sums to greater than 113 because respondents could check more than one age range when they care for more than one individual.

Compensated by Household Income



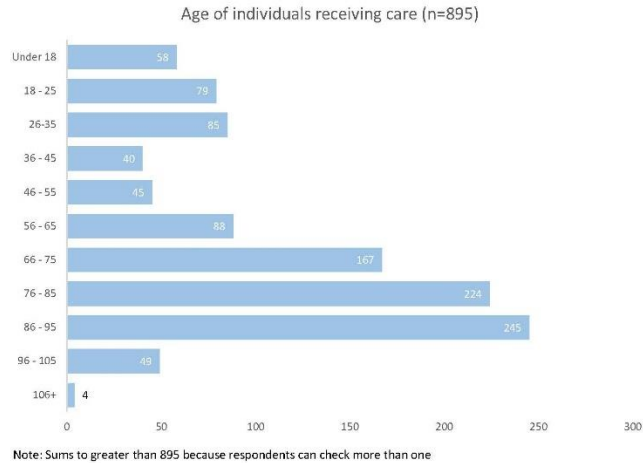
Of the 113 caregivers that indicated that they are compensated in any way for caregiving, 88 provided their household income. Caregivers making between \$50,000 and \$74,999 were the most common household income of those that are compensated for the care they provide with 21.6%. The least common household income of those that are compensated was those making over \$150,000 with 3.4%.

Characteristics of individual receiving care

- Age
- Impairment type
- Unmet needs
- Financial support
- Service utilization

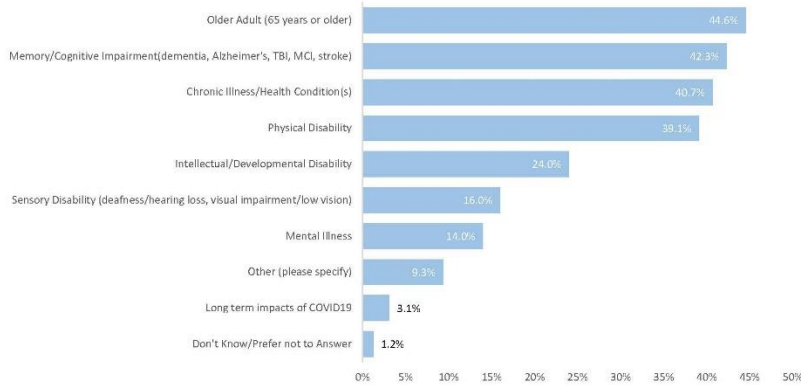
What age group(s) are the individual(s) you are caring for?

Almost three-quarters or 71.1% of the individuals receiving care were between the ages of 66 and 95. The most common age group of individuals receiving care were between the ages of 86 and 95 with 27.4% of respondents. 25.0% and 18.7% were 76 to 85 and 66 to 75. The least common age group was 106 and up and 36 to 45 years old.

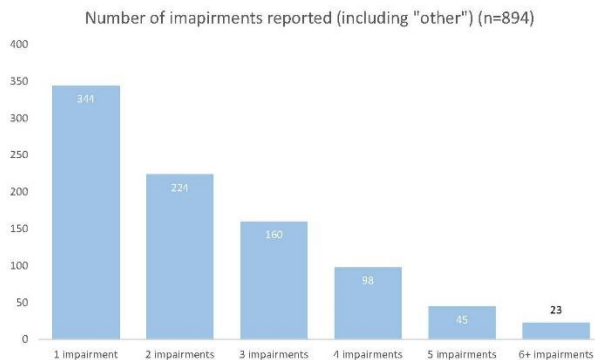


Impairment type

What is the impairment that requires you to provide care for the care recipient?
(n=900)



Number of impairments



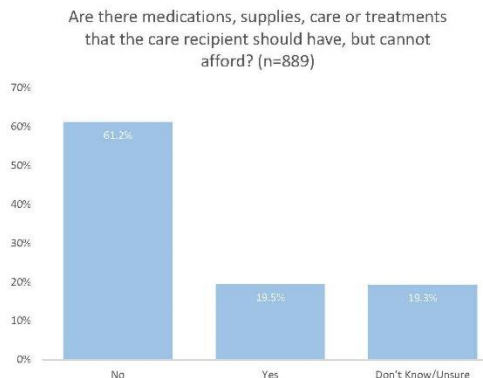
Note: In order to unduplicate, "other" impairments were only counted when it was the only impairment selected due to the fact that the other category was most often used to specify the specific diagnosis or impairment.

There was 344 or 38.5% of caregivers who identified one impairment type with fewer caregivers as the number of impairments increased. Two impairments were identified for 25.1% of responses, 17.9% identified three impairments, 11.0% four impairments, 5.0% five impairments and 2.6% identified 6 or more impairments.

61.5% of the respondents identified 2 or more impairments that require care.

Unmet needs

Almost 20% of the caregivers indicated that there are medications, supplies, care or treatments that the care recipient should have, but can't afford.



Unmet needs (continued)

• Top mentions:

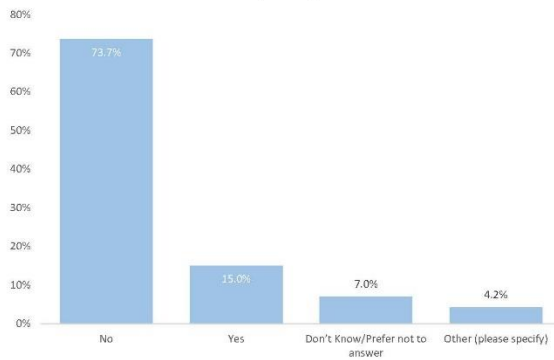
- Prescriptions not covered or partially covered by insurance (n=39)
- Medical, incontinence and other personal protective equipment/supplies (n=29)
- Home health aides (n=28)
- Therapies such as ABA, physical, speech & occupational (n=26)
- Home modifications (n=22)
- Mobility devices & Orthotics (n=18)
- Food, vitamins & supplements (n=10)
- Psychiatrists & psychologists that accept Medicaid (n=9)
- Hearing aids (n=9)

Other mentions:

- Mobility devices
- Medical & incontinence supplies
- Resilio
- Assistive device
- Transplant
- Home generator
- Transportation services & ADA van
- Home maintenance
- Wound care treatment
- Job training
- Biopap machine
- Mental health programs for youth
- Insurance premiums & copays
- Assisted living, LTC, hospice
- Medical marijuana
- Glasses
- Day activities
- Portable oxygen tank, with >70 min supply
- Eyeglasses
- Mental health and addiction medications
- Quality dental care & orthodontics
- Exercise equipment, gym memberships, exercise classes
- Hospital bed
- Feminine hygiene products
- Diabetes supplies & products

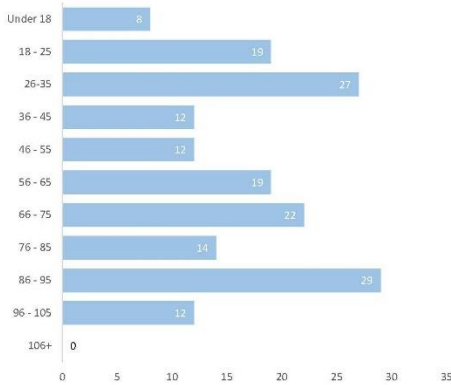
Financial support

Does your care recipient receive financial support from a program that contributes toward the cost of caregiving? (n=898)



Almost three-quarters (73.7%) of the caregivers that participated in the survey reported that the care recipient does not receive financial support from a program that contributes toward the cost of caregiving. 135 (15.0%) out of the 898 individuals that responded to this question did receive financial support.

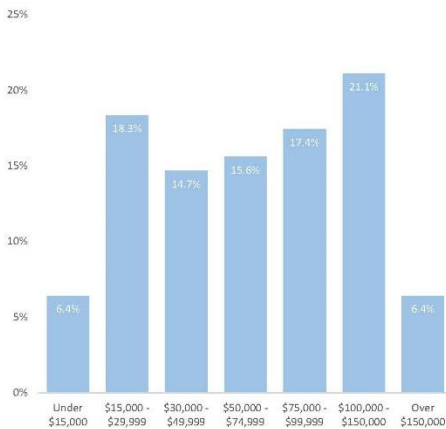
Received financial support by care recipient age



The care recipient was most often between the age ranges of 86 and 95 and 26 and 35 when the caregiver indicated that the care recipient receives financial support.

Note: Sums to greater than 135 because respondents could check more than one age range when they care for more than one individual.

Received financial support by income

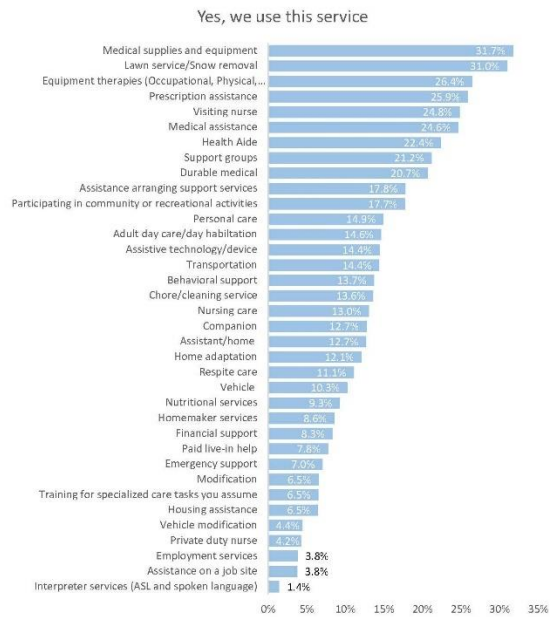


Caregiver's income was most commonly between \$100,000 and \$150,000 (21.1%) when the care recipient receives financial support. Incomes of under \$15,000 (6.4%) and over \$150,000 (6.4%) were the least common income when the care recipient received financial support.

Service utilization

The five most commonly utilized services were medical supplies and equipment (31.7%), lawn service/snow removal (31.0%), equipment therapies (Occupational, Physical, Cognitive, Speech) (36.4%), prescription assistance (25.9%) and visiting nurse (24.8%).

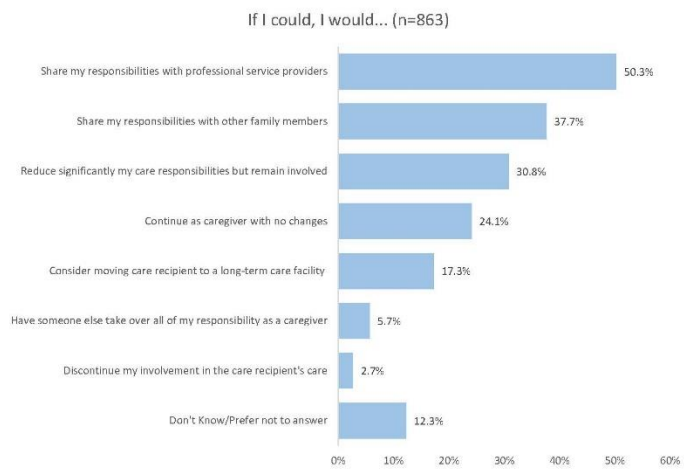
The services that were reported least commonly were vehicle modification (4.4%), private duty nurse (4.2%), employment services (3.8%), assistance on a job site (3.8%) and interpreter services (1.4%).



Note: Percentages sum to greater than 100 because respondents can check more than one

Preferences

About half (50.3%) of caregivers would share their responsibilities with professional service providers if they could. Another 37.7% said they would share responsibilities with other family members if they could. Only 5.7% of caregivers indicated that they would have someone else take over all of their responsibilities as a caregiver and 2.7% would want to discontinue their involvement in the care recipient's care if they could.



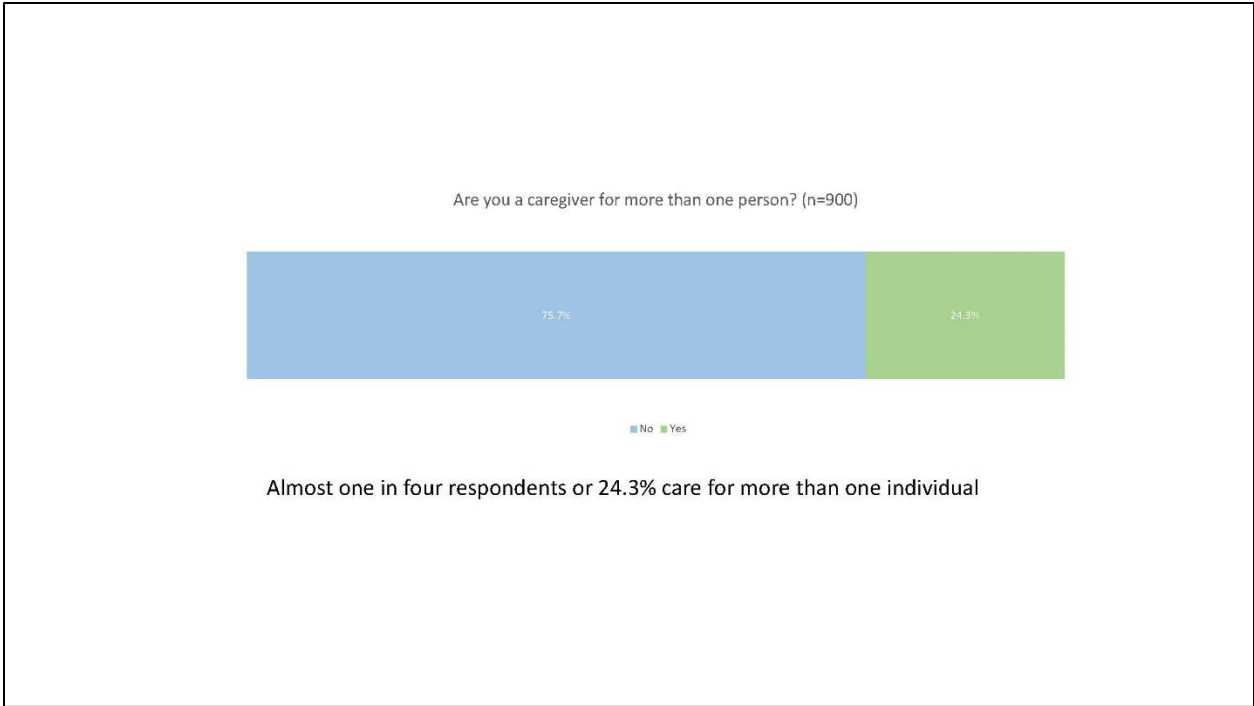
Note: Percentages sum to greater than 100 because respondents can check more than one

Impairment type by preferences

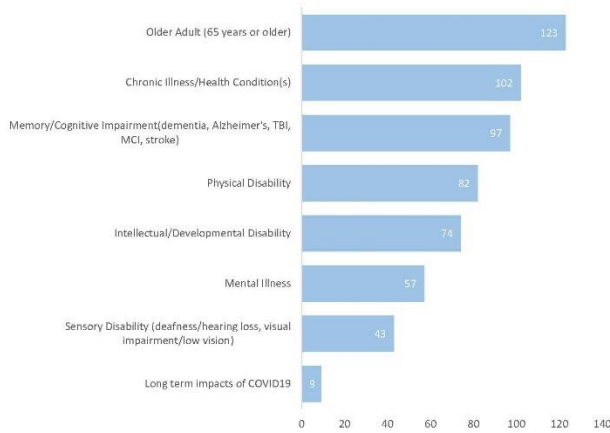
Impairment type by preferences	Older Adult (65 years or older)	Memory/Cognitive impairment (dementia, Alzheimer's, TBI, MCI, stroke)	Chronic illness/Health Condition(s)	Physical Disability	Intellectual/Developmental Disability	Sensory Disability (deafness/hearing loss, visual impairment/low vision)	Mental illness	Long term impacts of COVID19
Share my responsibilities with professional service providers	200	208	187	176	99	83	66	16
Share my responsibilities with other family members	154	167	141	133	63	66	42	11
Reduce significantly my care responsibilities but remain involved	127	130	114	112	60	56	47	11
Continue as caregiver with no changes	75	72	75	80	63	31	32	7
Consider moving care recipient to a long-term care facility	72	93	55	62	34	29	28	6
Have someone else take over all of my responsibility as a caregiver	23	27	21	28	11	16	12	2
Discontinue my involvement in the care recipient's care	10	16	9	12	5	6	6	1

Measuring and defining caregiving duties

- Share of multiple care recipients
- Duration of caregiving
- Hours per week
- Activities



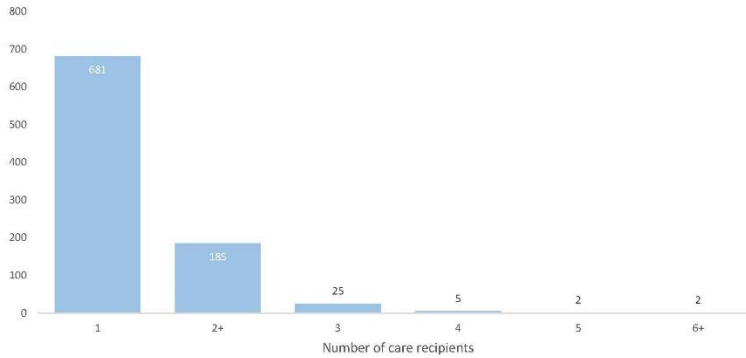
Cares for more than one individual by impairment type



In 123 out of the 219 responses where the caregiver indicated that they cared for more than one individual, they cared for an older adult over the age of 65. This might be because caregivers are caring for their parents which often means two individuals.

The second most common impairment type when there are more than one care recipient was chronic illness/health condition(s) with 102 responses.

Number of care recipients

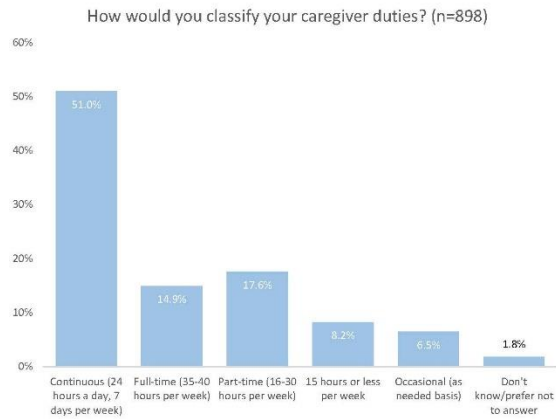


Of the 900 responses with information about the number of care recipients, 681 or 75.7% cared for one individual. There were 185 responses or 15.9% that cared for two or more individuals while progressively fewer cared for more than two individuals; 25 or 2.8% cared for three individuals and less than 1% cared for 4, 5 and 6 or more individuals each.

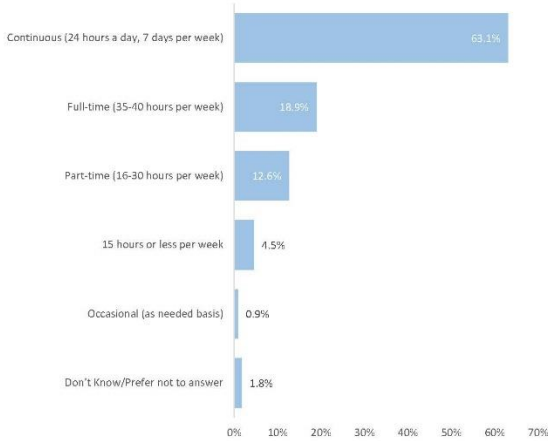
Note: There was 50 responses that indicated that they cared for more than one individual but did not indicate how many. They were added to the 2+ category.

Hours per week

More than half (51.0%) of the respondents indicated that they are continuously (24 hours a day, 7 days a week) a caregiver. 17.6% of the respondents said they are caregivers on a part-time basis (16-30 hours per week) and 14.9% on a full-time basis (35-40 hours per week). Respondents were least likely to be caregivers for 15 hours per week or less (8.2%) and occasionally on an as-needed basis (6.5%). Less than 2% said they don't know or prefer not to answer.

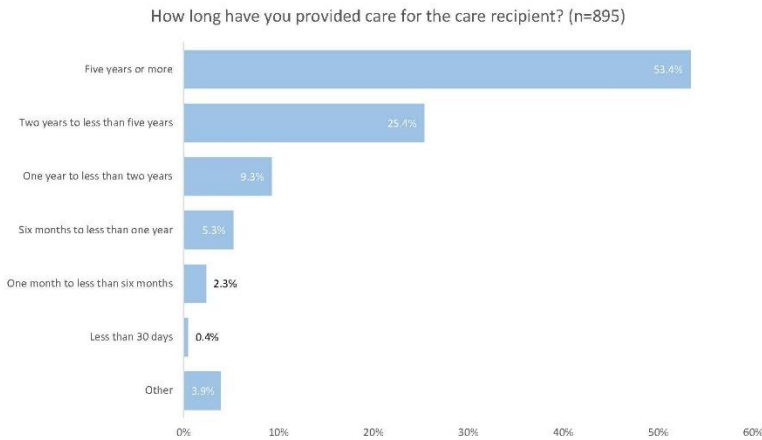


Compensated by time spent



Of the 113 caregivers who indicated that they are compensated in any way, 63.1% cared for an individual on a continuous basis. Another 18.9% indicated they cared for an individual on a full-time basis followed by part-time basis with 12.6% of the compensated caregivers.

Duration



More than half, or 53.4% of the caregivers indicated that they have provided care for more than five years. Progressively fewer respondents have provided care for less than 5 years.

Impairment type by duration

Impairment type by duration	Older Adult (65 years or older)	Memory/Cognitive Impairment(Dementia, Alzheimer's, TD, MCI, amnesia)	Chronic Illness/Health Condition(s)	Physical Disability	Intellectual/Developmental Disability	Sensory Disability (deafness/hearing loss, visual impairment/low vision)	Mental Illness	Long term impact of COVID19
Five years or more	193	165	198	170	73	86	83	12
Two years to less than five years	122	132	99	83	16	31	14	2
One year to less than two years	42	43	33	33	5	14	7	5
Six months to less than one year	24	22	24	15	4	5	6	5
One month to less than six months	4	22	5	8	0	2	5	1
Less than 30 days	2	1	3	3	1	1	1	1

Caregiver age by duration

Caregiver age by duration	Under 18	18 - 25	26 - 35	36 - 45	46 - 55	56 - 65	66 - 75	76 - 85	86 - 95	96 - 105	106+
Five years or more	0	1	9	33	100	181	102	41	4	0	1
Two years to less than five years	2	0	6	7	26	94	66	14	0	0	1
One year to less than two years	0	0	2	3	13	39	20	5	1	0	0
Six months to less than one year	0	1	3	3	6	18	9	6	0	0	0
One month to less than six months	0	0	0	2	2	7	7	3	0	0	0
Less than 30 days	0	0	0	2	1	0	0	0	0	0	0

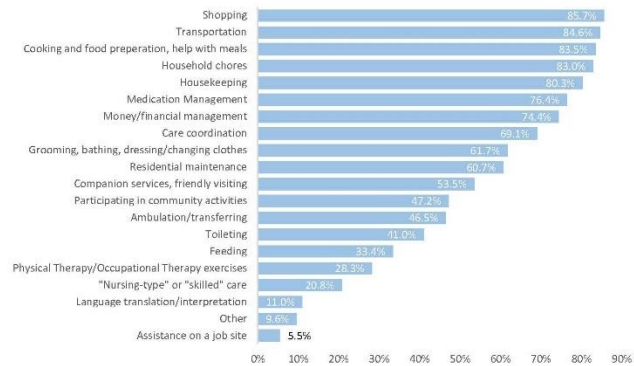
Age receiving care by duration

Age receiving care by duration	Under 18	18 - 25	26 - 35	36 - 45	46 - 55	56 - 65	66 - 75	76 - 85	86 - 95	96 - 105	106+
Five years or more	40	66	66	24	26	42	73	90	108	26	1
Two years to less than five years	4	4	7	5	13	29	50	65	78	9	1
One year to less than two years	1	0	1	0	0	4	69	31	27	6	1
Six months to less than one year	2	2	1	5	1	4	10	17	12	2	0
One month to less than six months	2	0	1	1	0	2	3	7	6	0	0
Less than 30 days	2	1	2	1	1	1	1	2	1	1	1

Activities

Shopping (85.7%), transportation (84.6%) and cooking and food preparation and help with meals (83.5%) were the three most commonly reported care giving activities.

Do you help your care recipient to do any of the following activities? (n=899)



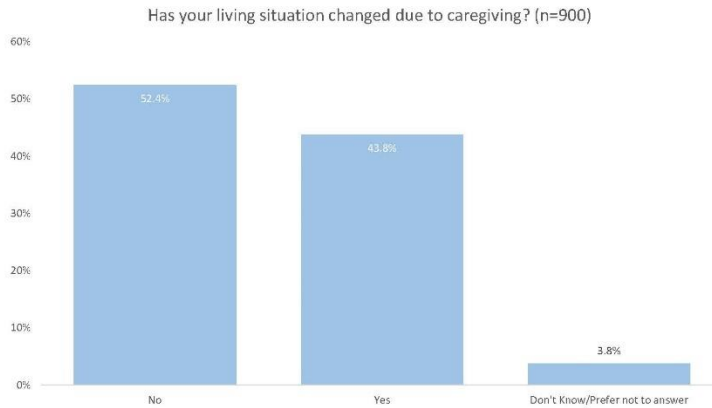
Activities (continued)

- Other activities included:
 - Supervision, general (n=6)
 - Supervision/help with recreation, leisure, social activities (n=6)
 - Crisis, behavioral intervention, ABA (n=5)
 - Revoicing/communication (n=2)
 - Taking care of pets (n=2)
 - Help with schoolwork (n=1)
 - Religious/spiritual care/support (n=1)

Impacts of caregiving

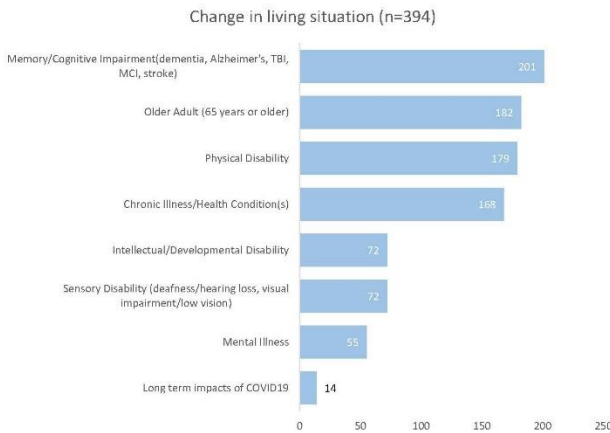
- Changes in living situation
- Employment interference and support
- Lost wages
- Personal funds
- Stress
- Other impacts

Living situation



About 44% of the respondents indicated that their living situation changed due to caregiving. Changes include moving in with the care recipient, the care recipient moving in with the caregiver, made renovations necessary for care and more.

Impairment type of those who indicated a change in living situation

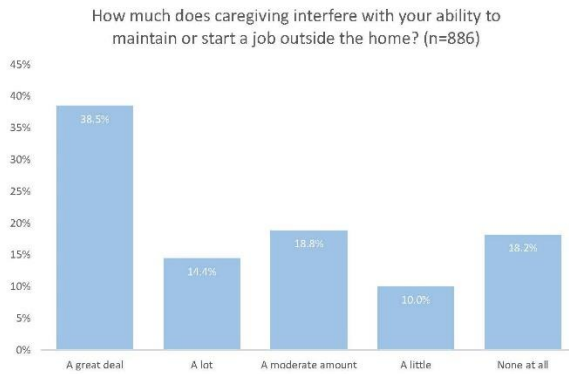


Note: Sums to greater than 394 because respondents can check more than one impairment type

Of the 394 responses that indicated they experienced a change in living arrangement, 201 caregivers, or 51.0% cared for an individual with a memory/cognitive impairment.

Another 46.2% were older adults aged 65 and older and 45.4% had physical disabilities.

Employment interference



81.8% of respondents indicated that caregiving interfered a little or more with their ability to maintain or start a job outside the home.

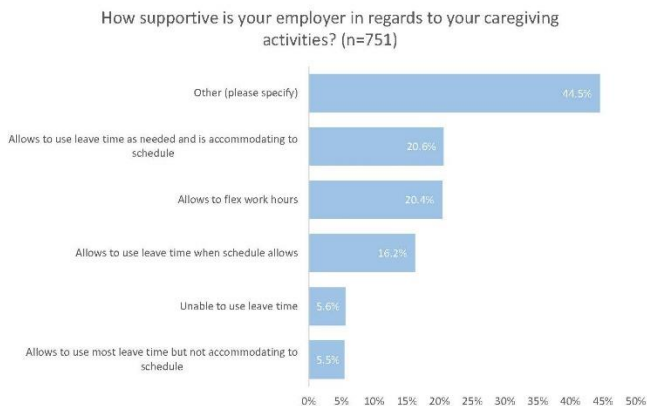
Job interference and employment status

Have you lost pay due to missing work for caregiving activities?	A great deal	A lot	A moderate amount	A little	None at all
Employed Full-time	72	55	101	59	41
Employed Part-time	45	21	20	7	12
Self-employed	31	6	8	5	2
Not employed (job searching)	25	8	13	4	--
Not employed (stay at home by choice)	32	5	4	1	5
Retired	119	30	20	13	95
Student	0	1	4	0	1

Employment support

Of the 751 responses to the employer support question, “Other” was the most common response with 334 responses or 44.5%.

The second most common response was allow to use leave time as needed and is accommodating to schedule (20.6%) and allows to flex work hours (20.4%). The least common responses was unable to use leave time (5.6%) and allows to use most leave time but not accommodating to schedule (5.5%).



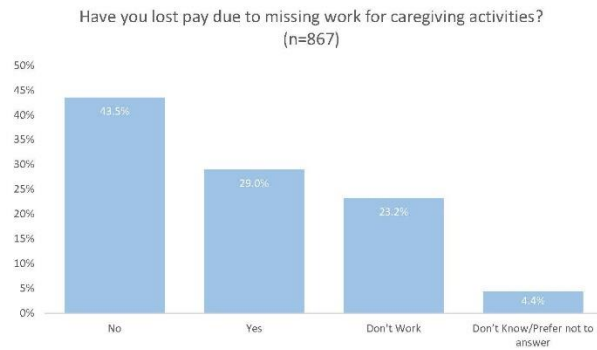
Note: Percentages sum to greater than 100 because respondents can check more than one

Employment support (continued)

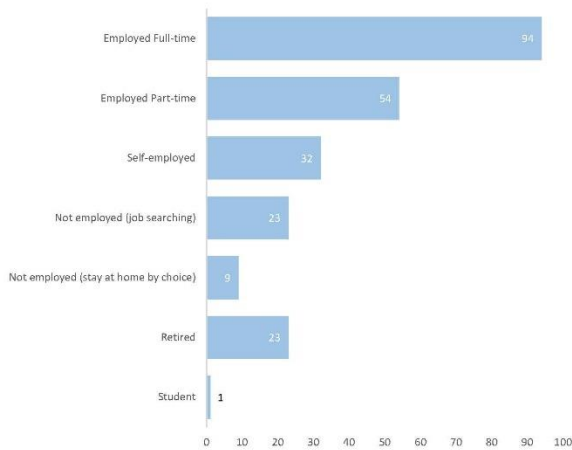
- Upon reviewing the “other” response, the following themes were identified
 - Retired, unemployed, not applicable (n=215)
 - Being self employed allows for adjustments when needed (n=23)
 - Working from home/remotely during the COVID-19 pandemic has resulted in added flexibility for some and reduced flexibility for others (n=10)
 - Ability to provide care outside of work hours or use paid sick time (n=8)
 - Not disclosing that they are a caregiver to employer (n=7)
 - Paid caregivers don’t need to modify work schedule at all (n=6)
 - Using FMLA time (n=1)

Lost wages

There were 251 individuals (29.0%) who indicated that they lost pay due to missing work for caregiving activities.

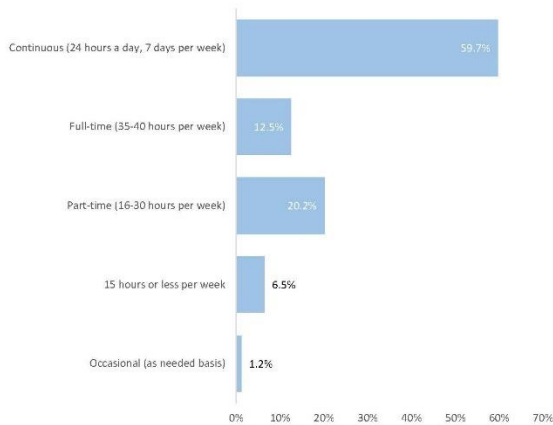


Lost wages and employment status



Of the respondents who indicated that they lost pay and provided their employment status, most were employed full time (n=94) and part-time (n=54)

Lost wages by time spent

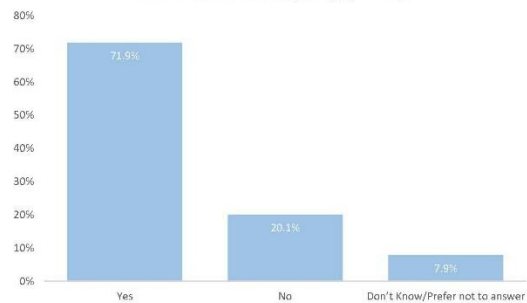


Of the 248 respondents who indicated that they lost pay and provided the length of time they've been caregiving, most worked as a caregiver continuously (59.7%) and part-time (20.2%).

Personal funds

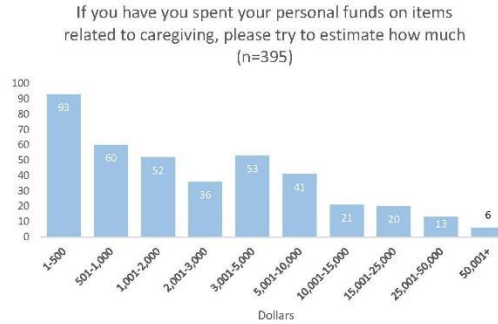
Over 70% of the caregivers that responded have spent personal funds on items related to caregiving. About 20% said they have not spent personal funds on caregiving related items.

In the past year, have you spent your personal funds on items related to caregiving? (n=894)

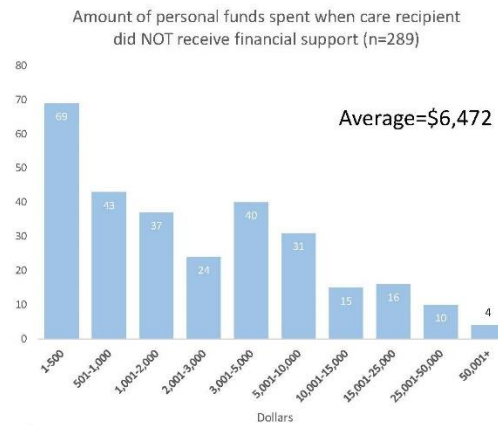
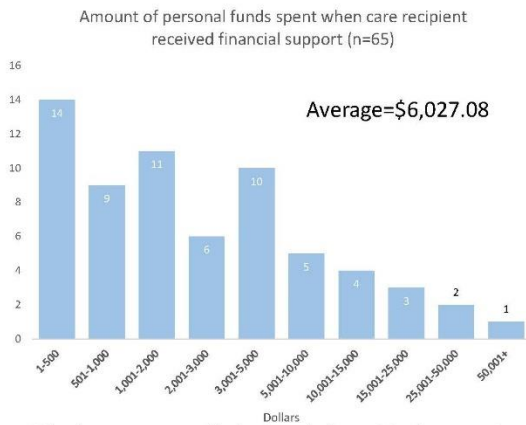


Personal Funds

There were 395 responses that provided a valid number of dollars spent on items related to caregiving. The average spending for the individuals who spent personal funds was \$6,297.38 per year while the median was \$2,000. The most common spending range of those that indicated they've spent personal funds on caregiving was between \$1 and \$500. Fewer and fewer people reported spending for each of the higher ranges.



Personal funds spent by financial support

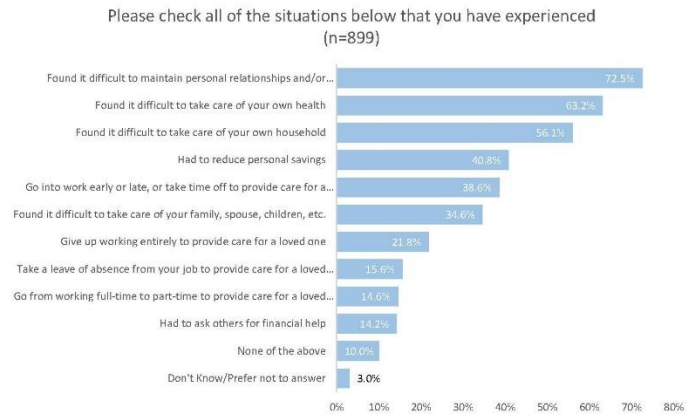


1. If you have spent your personal funds on items related to caregiving, please try to estimate how much.
2. Does your care recipient receive financial support from a program that contributes toward the cost of caregiving?

Impacts

Almost three-quarters (72.5%) of the caregivers who responded to the survey reported difficulty maintaining personal relationships and/or personal activities. More than 50% of caregivers reported finding it difficult to take care of their own health (63.2%) and household (56.1%). The least commonly reported responses were going from working full-time to part time (14.6%) and having to ask others for financial help (14.2%).

Only 10% of caregivers did not experience any of the situations listed.



Note: Percentages sum to greater than 100 because respondents can check more than one

Caregiver age by impacts

Caregiver age by impacts	Under 18	18 - 25	26 - 35	36 - 45	46 - 55	56 - 65	66 - 75	76 - 85	86 - 95	96 - 105	106+
Found it difficult to maintain personal relationships and/or personal activities	2	2	14	34	130	263	141	54	5	0	1
Found it difficult to take care of your own health	2	2	13	37	121	227	118	40	2	0	1
Found it difficult to take care of your own household	2	1	12	30	107	209	99	35	4	0	1
Had to reduce personal savings	2	1	12	28	86	131	77	26	0	0	0
Go into work early or late, or take time off to provide care for a loved one	1	1	11	29	107	161	28	7	0	0	1
Found it difficult to take care of your family, spouse, children, etc.	2	1	8	22	79	134	49	13	1	0	1
Give up working entirely to provide care for a loved one	2	0	8	10	23	85	56	12	0	0	0
Take a leave of absence from your job to provide care for a loved one	1	0	8	17	41	49	19	5	0	0	0
Go from working full-time to part-time to provide care for a loved one	2	1	1	9	30	68	15	3	1	0	0
Had to ask others for financial help	2	1	4	12	37	44	21	7	0	0	0

Care recipient age by impacts

Care recipient age by impacts	Under 18	18 - 25	26 - 35	36 - 45	46 - 55	56 - 65	66 - 75	76 - 85	86 - 95	96 - 105	106+
Found it difficult to maintain personal relationships and/or personal activities	45	59	61	26	25	67	109	159	170	29	2
Found it difficult to take care of your own health	42	56	49	23	29	60	103	143	139	33	3
Found it difficult to take care of your own household	37	50	48	19	24	46	79	130	127	31	3
Had to reduce personal savings	35	50	40	21	20	39	80	87	72	16	3
Go into work early or late, or take time off to provide care for a loved one	30	47	38	12	16	39	52	85	89	16	3
Found it difficult to take care of your family, spouse, children, etc.	33	38	31	12	15	31	42	87	82	14	2
Give up working entirely to provide care for a loved one	18	28	25	10	7	18	30	39	46	12	1
Take a leave of absence from your job to provide care for a loved one	17	35	16	11	8	15	27	28	31	5	1
Go from working full-time to part-time to provide care for a loved one	15	34	21	6	8	15	20	27	26	2	1
Had to ask others for financial help	18	23	15	9	9	19	25	24	24	4	2

Impairment type by impacts

Impairment type by impacts	Older Adult (65 years or older)	Memory/Cognitive Impairment(dementia, Alzheimer's, TBI, MCI, stroke)	Chronic Illness/Health Condition(s)	Physical Disability	Intellectual/Developmental Disability	Sensory Disability (deafness/hearing loss, visual impairment/low vision)	Mental Illness	Long term impacts of COVID19
Found it difficult to maintain personal relationships and/or personal activities	281	296	273	259	158	109	90	23
Found it difficult to take care of your own health	252	259	253	232	147	99	95	23
Found it difficult to take care of your own household	222	218	214	216	131	89	78	22
Had to reduce personal savings	153	155	170	158	107	60	73	19
Go into work early or late, or take time off to provide care for a loved one	150	143	148	121	93	47	58	12
Found it difficult to take care of your family, spouse, children, etc.	134	147	129	127	89	57	55	11
Give up working entirely to provide care for a loved one	82	88	89	89	64	44	27	8
Take a leave of absence from your job to provide care for a loved one	60	55	70	60	44	29	32	4
Go from working full-time to part-time to provide care for a loved one	48	51	57	62	49	16	25	4
Had to ask others for financial help	41	60	55	55	44	26	34	5

Hours spent caregiving by impacts

Hours spent caregiving by impacts	Continuous (24 hours a day, 7 days per week)	Full-time (35-40 hours per week)	Part-time (16-30 hours per week)	15 hours or less per week	Occasional (as needed basis)
Found it difficult to maintain personal relationships and/or personal activities	396	94	106	31	14
Found it difficult to take care of your own health	334	81	105	24	17
Found it difficult to take care of your own household	286	72	103	24	13
Had to reduce personal savings	233	53	59	11	7
Go into work early or late, or take time off to provide care for a loved one	169	47	75	36	13
Found it difficult to take care of your family, spouse, children, etc.	174	44	61	23	6
Give up working entirely to provide care for a loved one	146	27	16	3	1
Take a leave of absence from your job to provide care for a loved one	88	22	19	4	3
Go from working full-time to part-time to provide care for a loved one	78	16	31	4	2
Had to ask others for financial help	90	19	14	2	1

Duration by impacts

Duration by impacts	Five years or more	Two years to less than five years	One year to less than two years	Six months to less than one year	One month to less than six months	Less than 30 days
Found it difficult to maintain personal relationships and/or personal activities	359	161	58	30	18	4
Found it difficult to take care of your own health	318	141	42	30	13	4
Found it difficult to take care of your own household	278	117	48	30	12	4
Had to reduce personal savings	215	79	23	21	9	4
Go into work early or late, or take time off to provide care for a loved one	194	85	29	19	4	2
Found it difficult to take care of your family, spouse, children, etc.	176	76	25	14	8	3
Give up working entirely to provide care for a loved one	116	45	14	9	5	2
Take a leave of absence from your job to provide care for a loved one	83	32	11	7	0	2
Go from working full-time to part-time to provide care for a loved one	81	26	10	5	1	2
Had to ask others for financial help	81	25	7	11	1	2

Stress



When asked to rate their level of stress, caregivers most common rating was 10 indicating high stress levels. 60.5% of respondents rated their stress levels between 8 and 10.

The average stress rating was 7.57 and the median stress rating was 8.

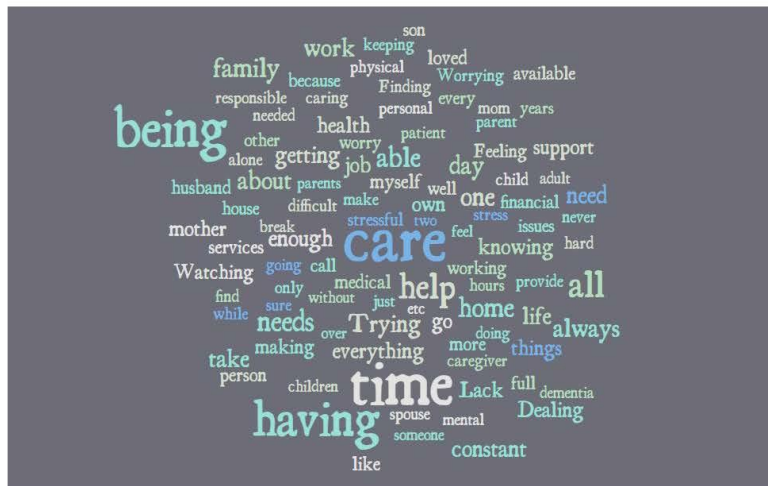
Stress by impacts

Stress by impacts	1	2	3	4	5	6	7	8	9	10
Found it difficult to maintain personal relationships and/or personal activities	0	6	6	15	24	35	91	138	122	180
Found it difficult to take care of your own health	5	2	6	7	21	28	64	125	112	175
Found it difficult to take care of your own household	0	3	5	8	17	26	62	111	93	155
Had to reduce personal savings	5	3	3	8	11	12	35	76	61	135
Go into work early or late, or take time off to provide care for a loved one	4	3	1	6	14	26	53	70	48	99
Found it difficult to take care of your family, spouse, children, etc.	0	3	1	2	13	12	37	58	65	105
Give up working entirely to provide care for a loved one	4	4	1	6	6	10	20	43	35	59
Take a leave of absence from your job to provide care for a loved one	4	1	0	2	1	8	17	23	22	55
Go from working full-time to part-time to provide care for a loved one	0	1	0	1	8	10	17	27	23	37
Had to ask others for financial help	2	0	1	3	2	6	11	22	18	58

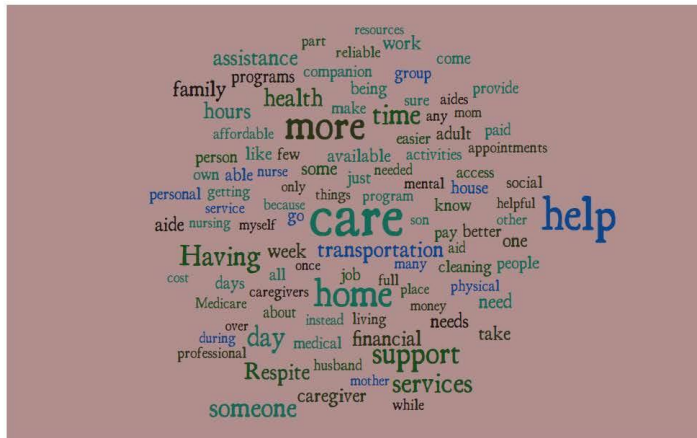
Stress by hours spent caregiving

Stress by hours spent per week caregiving	1	2	3	4	5	6	7	8	9	10
Continuous (24 hours a day, 7 days per week)	3	5	3	8	17	24	56	95	84	143
Full-time (35-40 hours per week)	6	3	4	7	6	11	22	32	20	17
Part-time (16-30 hours per week)	2	1	6	7	11	10	23	26	25	28
15 hours or less per week	0	4	8	2	5	11	14	13	1	6
Occasional (as needed basis)	4	4	10	5	6	7	6	4	2	2

What would you say is the most stressful aspect of being a caregiver?



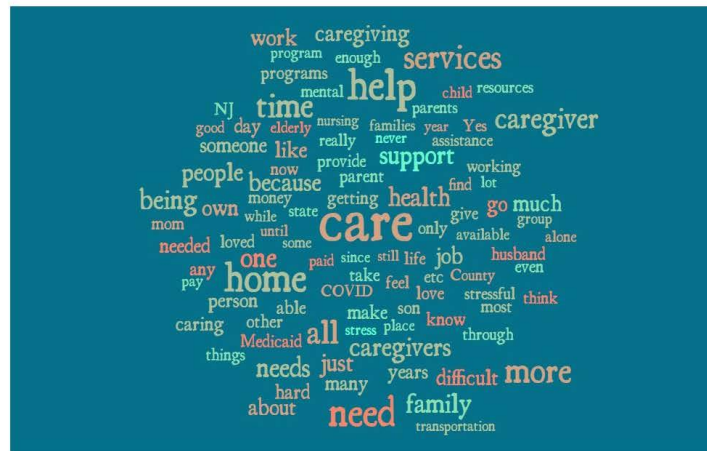
What kinds of alternative supports would make your role as a caregiver easier or assist with care to your loved one?



Immigration

- Is immigration status a barrier to access support services for the care recipient? If yes, please share more information on how it acts as a barrier.
 - In-home mental health supports for Spanish speaking seniors
 - Health care providers not accepting green cards as valid identification
 - Respondents would like to hire immigrant caregivers but can't do to their status
 - Support services that speak Spanish is hard to find

Is there anything else you'd like to share about your experiences as a caregiver? Is there anything you would like to share that we have not asked?



APPENDIX F: CAREGIVER TASK FORCE ACRONYM LIST

Caregiver Task Force Acronym List

AAA	Area Agency on Aging (AAA reads “Triple A”)
AADSP	Alzheimer’s Adult Day Services Program
ACL	Administration for Community Living
ADL	Activities of Daily Living
ADRC	Aging and Disability Resource Connection
AFN	Access and Functional Needs
AL	Assisted Living
APS	Adult Protective Services
CILS	Centers for Independent Living
CMS	Centers for Medicare & Medicaid Services
CNA	Certified Nurse Aide
CWA	County Welfare Agency
DCA	Department of Community Affairs
I/DD	Intellectual/Developmental Disabilities
DDD	Division of Developmental Disabilities
DDHH	Division of the Deaf and Hard of Hearing
DDS	Division of Disability Services
DHS	Department of Human Services
DMAHS	Division of Medicaid Assistance and Health Services
DME	Durable Medical Equipment
DMHAS	Division of Mental Health and Addiction Services
DoAS	Division of Aging Services
DSP	Direct Support Professional
I/A or I/R	Information & Assistance / Referral
IADL(s)	Instrumental Activity (Activities) of Daily Living (e.g. making phone calls, writing checks)
IDD	Intellectual and/or Developmental Disabilities
JACC	Jersey Assistance for Community Caregivers

LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer
LTC	Long Term Care
LTSS	Long Term Services and Support
LTCO	Long Term Care Ombudsman
MCO	Managed Care Organization
MFP	Money Follows the Person
MLTSS	Managed Long-Term Services and Support (Medicaid)
NF	Nursing Facility
NFCSP	National Family Caregiver Support Program (Title III E of the Older Americans Act)
NJ OEM	NJ Office of Emergency Management
NWD/SEP	No wrong Door/Single Entry Point
OAA	Older Americans Act
OCCO	Office of Community Choice Options
OPG	Office of the Public Guardian and Elder Rights
PAAD	Pharmaceutical Assistance to the Aged and Disabled Program
PACE	Program of All Inclusive Care for the Elderly
PCA	Personal Care Assistant
PEP	Participant Employed Provider
PPP	Personal Preference Program (component of the PCA state benefit)
RN	Registered Professional Nurse
SRCP	Statewide Respite Care Program
SSA	Social Security Administration
SSDI	Social Security Disability Income
SSI	Supplemental Security Income
SUA	State Unit on Aging
TBI	Traumatic Brain Injury
Title III E	National Family Caregiver Support Program
VA	Veterans Administration
VNA	Visiting Nurse Association

Please note - this list is not comprehensive; it is a reference for the New Jersey Caregiver Task Force Report

APPENDIX G: TESTIMONY THEMES

Themes Gathered from Caregiver Testimony

Caregivers need improved access to information and resources:

Caregivers report that they either don't know where to find help or that the avenues to find help are too complex. Some feel that caregivers have to be "connected" to get any help and they don't know how to start the process.

Caregivers feel that there are very limited supports for the caregivers. They would like to see more educational and informational opportunities so they can learn more about needs of the care recipient, what is available to help them and where they can connect with other caregivers in the community.

Caregivers report an overwhelming sense of isolation and loneliness. There are many caregivers who are struggling but they don't see themselves as caregivers so they just "soldier on" and don't consider seeking assistance.

In addition to feeling overwhelmed by the actual act of caregiving, caregivers often feel anxious, frustrated, angry, depressed and hopeless. Caregivers share that sometimes this is due to the situation their care recipient is facing but others report it stems from the effect caregiving responsibilities have had on their life.

Caregivers report that they receive little to no instruction on caring for their care recipient and handling issues that arise. They don't know what to do, how to do it, or any strategies for dealing with the care recipient's health/mental health/behavioral health, etc.

Caregivers need improved access to supports and services for the care recipient:

Caregivers report that service systems are too complex. Paperwork for applications, reporting requirements, and ongoing eligibility is overwhelming. They feel that the existing care systems don't acknowledge that caregiving responsibilities are monumental and that caregivers don't have the time, energy, resources or understanding to fulfill all of these requirements. Service systems can be "in silos", making it difficult to receive services for someone with multiple issues.

Caregivers shared that services often differ from county to county or even provider to provider making it very difficult and complicated for the caregiver to determine what help is available and how to access it.

As care recipient's needs change it is very difficult to adjust services to appropriately meet their needs. There is often very little assistance and information during transitions to affect a successful outcome. Some caregivers report that service systems don't take into account the long term needs of care recipients. As services are delivered and the care recipient is stabilized or does better, service hours may be reduced. This does not take into consideration that the reason the person may be doing better is because they are receiving the service and that if the services is reduced or removed the situation will deteriorate.

Caregivers report struggles with the care workforce. They feel there are not enough paid care staff and paid care staff may not be adequately trained to care for the care recipient in the manner the caregiver would. Funding mechanisms such as Medicaid significantly limit access to care due to low rates that cannot compete with caregivers or care recipients who are privately paying for care.

Caregivers need improved financial and legal resources:

Caregivers report that they are unemployed/underemployed because of caregiving responsibilities. Many have had to quit jobs, switch to part time, take lower paying jobs, or have

been unable to accept better jobs because of caregiving responsibilities. Inflexibility of many employers in regard to a caregiving lifestyle can make caregiving more difficult.

Caregivers report that they have had to pay out of pocket for supports, supplies and services for their care recipient. Many report they can't get supports because they can't afford them.

Caregivers report tremendous confusion and anxiety related to legal issues such as guardianship, power of attorney, representative payeeship, etc. They are concerned about finding trustworthy assistance and many don't have the financial resources to obtain legal assistance.

Very few caregivers consider succession planning but are concerned about the future of the care recipient, especially after the caregiver has passed on. This is particularly challenging when caregivers have had to utilize funds to take care of their care recipient that were meant for retirement or their own future needs.

Other important themes:

Caregiving would benefit from a holistic approach that looks at the individual served, the caregiver, other family and/or household members, etc. This approach would enable the caregivers to honestly and appropriately identify their needs, possible avenues of support and issues that need to be addressed. Many who testified shared a need for assistance with items that are not easily solved through the existing systems. These included care for short periods of time (for example from first thing in the morning until the bus for the day program arrives), assistance with household tasks, and assistance with paperwork. Some caregivers suggest looking at ways to promote greater community support for caregivers whether it be volunteer caregivers, professionals lending their expertise, community groups providing respite and support, or other ideas to support the caregivers' health and well-being.

COVID19 has impacted caregivers:

During the COVID-19 pandemic, caregiving became exponentially more difficult. Caregivers shared testimony about how existing issues caregivers face were compounded by supports and services being suspended and care recipients were home 24/7 with caregivers. In addition, caregivers faced incredible anxiety regarding keeping their care recipient and themselves safe.

Other areas of concern were testing and vaccine access. Many care recipients and caregivers could not access testing and vaccines through the traditional methods and there were few alternatives available. There was also a great deal of conflicting information or misinformation, making it very difficult for caregivers to make informed decisions.

Caregivers recommended that experiences and lessons learned from the COVID-19 pandemic must be researched, collected and utilized to develop a comprehensive plan for the future.

The themes gleaned from this testimony, in addition to results from the survey and their own professional knowledge, informed the Task Force as they developed the recommendations later in this report. In addition to the recommendations that the Task Force developed and prioritized in response to testimony, caregivers shared some specific ideas of their own that are listed below.

Through their testimony, caregivers made the following specific recommendations:

- Increase supports and services to educate, inform and support caregivers.
- Increase funding for programs and services aimed at caregivers and care recipients.
- Create one place (website, phone number, physical location) to go to find out about supports for caregivers.
- Develop outreach efforts that are accessible to everyone regardless of language, age, geography, socio-economic, education, family structure, level of technology, etc.

- Increase information about caregiver support groups.
- Increase cross system/provider training and education. Develop a “no wrong door” approach that ensures that any point of contact a caregiver reaches out to, they are knowledgeable about where to refer the caregiver.
- Promote messaging that validates the struggles of caregivers and helps caregivers to recognize they are caregivers. Create a universal definition of caregiving that includes both acute, long term and lifelong. It also recognizes that caregiving can be full time, part time, or temporary. It can be in the caregiver’s or care recipient’s home but caregiving can also take place long distance.
- Recognize that caregivers may be dealing with their own mental health issues and develop ways to address them.
- Obtain feedback from caregivers on ways to simplify access and navigation of systems, and then implement those changes. Include information as to where caregivers might see information and develop outreach plans that incorporate these venues.
- Institute better communication and coordination between service systems to facilitate better care for care recipients with complex and/or lifelong needs. Make systems more transparent.
- Develop and implement better “aging-out” and transition practices. Determine where applications or information can be streamlined so that caregivers are not faced with having to apply or re-apply every time they are looking for assistance.
- Develop information and planning tools to assist caregivers in developing succession plans for both short term and long term caregiving.
- Encourage a greater value placed on the role of paid care staff, including an increase in training, wages and benefits. Create mechanisms for career paths for DSPs, including certifications.
- Develop tax credits or changes in tax policy to benefit caregivers. Research tax credits for workers employed in direct care and possibilities for accessing benefits programs for health care.
- Create simpler and more universal mechanisms for caregivers to be compensated for caregiving.

APPENDIX H: CAREGIVER DAY IN THE LIFE

A day in the life...

of the Caregiver of a 28-year-old non-verbal care recipient with Developmental Disabilities

5:00 am	Wake up. This is my “self-care” time, and I get myself going. I get things ready for the day for my son. I fill the juice cups, get his medicines organized, make food for the day.
6:00 am - 7:00 am	Wake son up. Bathe son: my son can step into the tub himself, but then I have to wash him and help him out of the tub. Then I put his medicated cream on him, diaper and get him dressed. I brush his teeth, and then strip his bed. Due to his inability to use the bathroom, I have to change his linens daily.
7:00 am - 7:00 pm	Meals. Due to my son’s nutritional needs and feeding limitations, he eats 7-9 sandwiches, cut up into small pieces – each day. He drools and is a messy eater, which requires me to change his outfits several times a day.
	<p>Activities.</p> <ul style="list-style-type: none"> • He uses his I-pad during the day for engagement and enrichment activities. I make sure it is charged and manage its use throughout the day. • If it is a good day – we may go out for a drive. • I change his diaper every 30-60 minutes. <p>Care Assistance. If I need to go food shopping, my mother comes over to help. Since she is not physically able to care for my son, I put him in the car, and she drives around with him, while I go food shopping.</p> <p>Safety. My son cannot be left alone. We have a Nest camera in our house, so I can be in a different room than him in the house. This enables me to be upstairs changing his sheets or cleaning, or in the kitchen making dinner - and still be watching him. This enables me to leave the room, and run back when he needs assistance.</p> <p>Ordering supplies. During the day – I have to find time to get online and order the supplies that my son needs, especially incontinence supplies, which are used quickly and need to be kept in stock in the house. I also manage his medical appointments and prescription refills.</p>
7:00 pm	Night routine. I bathe my son again. I shave him, brush his hair and teeth – as he is unable to do this on his own.
8:00 – 9:00 pm	My son goes into bed, and falls asleep watching a movie on his I-pad.
8:00 – 10:00 pm	This is my time. I try to read, watch TV, take a shower. And take deep breaths before the next day.

“The social isolation of my life, even prior to the pandemic, is similar to the isolation that many people got to experience during the lockdown.” – Kathi L.

APPENDIX I: PROGRAMS FOR CAREGIVERS IN NEW JERSEY

Programs Serving Caregivers in New Jersey

Within the [New Jersey Department of Human Services](#), there are multiple divisions that have programs that assist caregivers directly and through services to care recipients.

[Catastrophic Illness in Children Relief Fund \(CICRF\)](#) is a financial assistance program for New Jersey Families with potentially catastrophic medical expenses due to a child's illness or condition.

[Commission for the Blind & Visually Impaired \(CBVI\)](#) promotes and provides services in the areas of education, employment, independent living and eye health through informed choice and partnership with persons who are blind or visually impaired, their families and the community.

[Division of Aging Services \(DoAS\)](#) administers a number of federal and state-funded programs that make it easier for older adults to live in the community as long as possible with independence, dignity and choice.

[Division of the Deaf & Hard of Hearing \(DDHH\)](#) provides education, advocacy and direct services to eliminate barriers and promote increased accessibility to programs, services, and information routinely available to the state's general population.

[Division of Developmental Disabilities \(DDD\)](#) *assures the opportunity for individuals with developmental disabilities to receive quality services and supports, participate meaningfully in their communities and exercise their right to make choices.*

[Division of Disability Services \(DDS\)](#) provides a single point-of-entry for people seeking disability related information in New Jersey. DDS serves individuals with all disabilities, statewide. DDS works to streamline access to services and information that promote and enhance independent living for individuals with disabilities by facilitating coordination and cooperation among local, county and state government agencies.

[Division of Family Development \(DFD\)](#) provides leadership and supervision to the public and non-profit agencies that deliver financial assistance and critical safety net services to individuals and families in New Jersey.

[Division of Mental Health and Addiction Services \(DMHAS\)](#) oversees New Jersey's adult system of community-based behavioral health services. These agencies provide a full array of services, including substance use disorder prevention and early intervention, emergency screening, outpatient and intensive outpatient mental health and addictions services, partial care and partial hospitalization, case management, medication assisted treatment for substance use disorder, and long and short term mental health and substance use disorder residential services, in addition to other evidence-based practices such as the Program for Assertive Community Treatment (PACT), supported employment and education, and supportive housing.

[Division of Medical Assistance & Health Services \(DMAHS\)](#) administers Medicaid's state-and federally- funded [NJ FamilyCare](#) programs for certain groups of low- to moderate- income adults and children. Through these programs, DMAHS serves approximately 1.7 million, or nearly 20%, of New Jersey's residents.

Within those division's there are a number of unique programs that serve caregivers and care recipients.

[Managed Long Term Services and Supports \(MLTSS\)](#) refers to the delivery of long-term services and supports through New Jersey Medicaid's NJ FamilyCare managed care program. MLTSS is designed to expand home and community-based services, promote community inclusion and ensure quality and efficiency. Respite may be available to through your [MCO](#) as part of [Medicaid](#), [NJ Family Care](#) (these include MLTSS and the Community Care waiver)

[Personal Assistance Service Program \(PASP\)](#) is a personal care assistance program that provides up to 40 hours per week of routine, non-medical personal care assistance to adults with permanent physical disabilities who are 18 years of age or older, who are employed, preparing for employment, attending school or involved in community volunteer work and who are able to self-direct their own services.

The [Statewide Respite Care Program](#) offers a periodic break for caregivers through a sliding scale payment model. More information can be found at the following link: [New Jersey Respite Care Brochure](#)

[Jersey Assistance for Community Caregiving \(JACC\)](#) offers a broad array of in-home and community-based services to individuals age 60 and older who meet clinical eligibility for nursing home level of care and who desire to remain in their homes within the community. More information can be found at the following link: [JACC Brochure](#)

The [Alzheimer's Adult Day Services Program](#) is another option for caregivers of individuals with dementia or related disorders who would like to send their loved one to an Adult Day Center.

In each county, the [Area Agency on Aging/Aging and Disability Resource Connection](#) offers caregiver services through the Older Americans Act Title III E National Family Caregiver Support Program. More information can be found at the following link: [ADRCNJ.org](#)

Services may also be available through Veterans Affairs for caregivers of veterans. This may be through the Program of Comprehensive Assistance for Family Caregivers (PCAFC) or through the Veteran's Directed Care Program. More information can be found at the following links:

- [VA Caregiver Support Program](#)
- [Lyons Campus of the VA New Jersey Health Care System](#)

The network of regional Veterans Service Offices (VSO), through the NJ Department of Military and Veterans Affairs (DMAVA) provides the state's Veterans and their dependents with information and guidance on employment, education, burial, counseling, housing, social and medical services and more. A list of local VSOs can be found at the following link:

- [County Veterans Service Offices](#)

The [Children's System of Care](#) (CSOC) serves children and adolescents with emotional and behavioral health care challenges and their families; children with developmental and intellectual disabilities and their families; and, children with substance use challenges and their families in order to provide services based on the needs of the child and family in a family-centered, community-based environment.

[The Family Resource Network](#) serves as the New Jersey Lifespan Respite Coalition under the name Caregivers of New Jersey. That is a coalition of organizations that promote services and support for family caregivers. More information can be found at the following links: [Caregivers of New Jersey](#)

[New Jersey Family Leave Insurance Program](#) provides New Jersey workers cash benefits for up to twelve weeks to bond with a newborn or newly placed adoptive, or foster child, or to provide care for a seriously ill (including COVID-19) or injured loved one.

The [New Jersey Paid Sick Leave](#) law assures that employers of all sizes must provide full-time, part-time, and temporary employees with up to 40 hours of earned sick leave per year so they can care for themselves or a loved one.

A number of community based organizations provide services and supports for caregivers in New Jersey. A few are listed below:

[Care2Caregivers](#) is a free, confidential help line for anyone concerned about or caring for someone with memory issues. The hotline can be reached at [1.800.424.2494](tel:1.800.424.2494)

The [Self-Help Group Clearing House](#) helps people find and form all types of self-help support groups in order to provide hope, strength and experience to those in need in order to not feel alone.

[AARP New Jersey](#) educates and advocates on behalf of those 50+ on issues that are important to them, their families, and to all Garden State residents.

[Alzheimer's Association, Greater New Jersey Chapter](#) helps and supports people with Alzheimer's and Related Disorders and their caregivers. The Alzheimer's Association leads the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

[Alzheimer's New Jersey](#) aims to improve the lives of people in New Jersey who are affected by Alzheimer's disease and other dementias; offering continuous hope, and support. responds to the needs of people in New Jersey who are affected by Alzheimer's disease and other dementias, by providing programs and community partnerships that increase awareness and access to services.

[Leading Age](#) is dedicated to advancing quality aging services in New Jersey and Delaware through advocacy, education and fellowship. LeadingAge New Jersey & Delaware is the statewide association of not-for-profit senior care organizations and is dedicated to advancing quality aging services in New Jersey and Delaware through advocacy, education and fellowship.

[The Arc of New Jersey](#) is the state's largest organization advocating for and serving children and adults with intellectual and developmental disabilities and their families. The Arc of New Jersey promotes and protects the human rights of individuals with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes; and is committed to enhancing the quality of life of those individuals and their families through advocacy, empowerment, education and prevention.

[NAMI New Jersey \(NAMI NJ\)](#) is a statewide non-profit organization dedicated to improving the lives of individuals and families affected by mental illness.

Assistance with legal and financial issues relating to caregivers may be available through the following legal service organizations:

[Legal Services of New Jersey](#) coordinates the statewide Legal Services system, which provides free legal assistance to low-income New Jerseyans for their civil legal problems.

- [South Jersey Legal Services](#)
- [Legal Services of North West Jersey](#)
- [Essex-Newark Legal Services](#)
- [Central Jersey Legal Services](#)
- [North East New Jersey Legal Services](#)

[Community Health Law Project](#) is a statewide not-for-profit advocacy and legal service organization which provides legal representation and advocacy services to low-income individuals with disabilities and the frail elderly.

APPENDIX J: ACL FEDERAL CAREGIVER SUPPORT INVENTORY

Appendix

Inventory of Federal Caregiver Support Programs and Initiatives

Prepared by
The Administration for Community Living

In coordination with
The RAISE Family Caregiving Advisory Council





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Background and Overview

When Congress passed the [Recognize, Assist, Include, Support, and Engage Family Caregivers Act](#), it established the Family Caregiving Advisory Council (the council) and authorized the development of a National Family Caregiving Strategy by federal agencies in collaboration with the council. When this strategy is established and implemented, federal, state, and local partners will take steps to assist family caregivers in providing the best care possible while supporting their own physical and mental health, emotional well-being, and financial needs in the process.

An important step in the development of the strategy is to identify and document existing federal programs and initiatives that assist family caregivers. Specifically, the RAISE Act called for:

“The Advisory Council’s initial report under paragraph (1) shall include— (A) an inventory and assessment of all federally funded efforts to recognize and support family caregivers and the outcomes of such efforts, including analyses of the extent to which federally funded efforts are reaching family caregivers and gaps in such efforts.”

This document presents information about more than 50 federal programs and initiatives collected by the council with support from the Administration for Community Living (ACL).

TERMINOLOGY USED IN THIS INVENTORY

In this document and throughout the council’s work, the word “family” is used broadly to denote those with biological or legal connections and families of choice. It also acknowledges the fact that “family caregiver” is not the same as “next of kin.” The person receiving support has the right to decide and designate who their preferred family caregiver is—it should never be decided by social services or medical professionals.

The council uses the term “family caregiver” in its broadest and most inclusive sense to encompass:

“All unpaid individuals of all ages who are caring for individuals with disabilities, chronic or other health conditions, and/or functional limitations.”

This term includes family members, partners, friends, kinship and grandfamily caregivers, and the untold millions of youth across the nation who care for family members regardless of the type of assistance needed. It includes part-time caregivers and full-time caregivers. While it is used as a singular noun in this report, the council also recognizes that in some families, multiple individuals serve in this role.

However, it is important to note that the program descriptions that follow the introductory material in this document were submitted by individual agencies. Some federal programs define “family caregiver” as required under statute. When defined in statute, the definition may differ from the definition used elsewhere in this document.

Incremental Progress in Recognizing Family Caregivers

With the passage of the RAISE Act, Congress took an important step in continuing more than four decades of legislative progress on behalf of family caregivers. In 1966, President Lyndon B. Johnson established what is now known as the President’s Committee for People with Intellectual Disabilities (PCPID). This committee advises the President on ways to improve the quality of life experienced by people with intellectual disabilities and their families.

While the Great Society programs of the 1960s did not include specific provisions for caregivers, by 1975 Congress had amended the [Older Americans Act](#) (OAA), which was signed into law in 1965, to include funding for adult day care services. While the statute did not directly refer to adult day care as respite care for caregivers, it laid the groundwork to providing caregivers options for addressing their respite and related needs.

In 1978, Congress clarified the use of adult day services as a form of family respite care, placing it within a coordinated system of community long-term care services. This was significant because it formally established investments in the well-being of the family caregiver as a means of supporting the person receiving support. Additional amendments to the OAA in the 1980s further solidified recognition—supported by research—of the significant positive impact the well-



being and ability of caregivers can have on people living with Alzheimer's disease and related dementias. Expansions to Medicare and Medicaid in the 1980s continued the process of beginning to formally recognize the role of family caregivers. In 1981, family caregivers benefited indirectly from the addition of Medicaid's home and community-based services waiver programs. The following year, Congress added a hospice benefit to Medicare that specifically included respite care for caregivers.

In 1990, the passage of the [Americans with Disabilities Act \(ADA\)](#) prohibited, among other things, discrimination of a caregiver based on "association with" an individual with a "disability" as defined by the ADA.

This increasing recognition of caregivers continued through the 1990s with the inclusion in the OAA of training, counseling, and information services for caregivers, in addition to in-home respite care and expansion of eligibility limits. The [Family Caregiver Support Act of 1993 \(S.1072\)](#), for example, sought to amend the Social Security Act to enable states to establish programs to support unpaid caregivers. Also in 1993, the [Federal Family and Medical Leave Act](#) established worker rights of up to 12 weeks of unpaid, job-protected leave to care for oneself or certain family members: child, spouse, or parent. During that time, a number of states rolled out caregiver initiatives offering such services as respite, information and resources, support groups, case management, and education and training programs.

In June 1999 a landmark Supreme Court decision in [Olmstead v. L.C., 527 U.S. 581](#) held that "unjustified segregation" of people with disabilities is against the law under the ADA. As a result, many states have expanded their home and community-based services (HCBS) systems as part of their larger efforts to achieve *Olmstead* compliance.

The establishment of the [National Family Caregiver Support Program](#) (NFCSP) in 2000 marked a significant expansion in support for family caregivers by formally recognizing family caregivers and providing a range of services to allow them to help their family members remain independent for as long as possible. These services include connecting caregivers to private and voluntary agencies that can assist them, counseling and training, and respite care options. Even more importantly, NFCSP funding is provided to every state, territory, and tribe, requiring the establishment of a basic set of services and supports available to family caregivers.

That same year, the [Developmental Disabilities Assistance and Bill of Rights Act of 2000 \(DD Act\)](#) stipulated that the [56 State DD councils](#) include representation by people with disabilities and their caregivers, guardians, and/or parents, paving the way for more family-centered community services, individualized supports, and other forms of assistance (ACL, 2017).

In 2006, the Lifespan Respite Act expanded access to respite to people of all ages across the nation. It sought to increase availability of respite options for family caregivers of children and adults with physical, cognitive, and intellectual disabilities.

In 2010, the [Caregivers and Veterans Omnibus Health Services Act \(PL 111-163\)](#) directed the U.S. Department of Veterans Affairs to establish a Program of General Caregiver Support Services (PGCSS) and a Program of Comprehensive Assistance for Family Caregivers (PCAFC), collectively referred to as VA's Caregiver Support Program (CSP), thus establishing caregiver support in the nation's largest integrated health care system. The National Academies of Sciences, Engineering, and Medicine convened an expert committee in 2014 to examine what is known about the nation's family caregivers of older adults. The final report, [Families Caring for an Aging America](#), found that while the need for family caregivers across the nation is growing, efforts to address that need proactively were modest at best. Accordingly, the report recommended that Congress convene a council to develop a National Family Caregiving Strategy (National Academies of Sciences, Engineering, and Medicine, 2016). That recommendation engendered the passage of the RAISE Family Caregivers Act of 2017.

Not all legislative activity on behalf of family caregivers has occurred at the federal level. Numerous states have begun enacting legislation to better recognize and support family caregivers. In 2014, AARP successfully advocated for the [Caregiver Advise, Record, Enable \(CARE\) Act](#) to support caregivers when patients go into the hospital and to help caregivers



understand what will be needed when patients are discharged to their homes (Reinhard, Young, Ryan, & Choula, March 2019). While provisions vary by state, to date 44 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands have implemented CARE Act policies that require hospitals to advise people of their opportunity to identify a family caregiver (Reinhard, Young, Ryan, & Choula, March 2019).

The forthcoming National Family Caregiving Strategy will build on these previous efforts and the significant achievements from states such as Pennsylvania, Wisconsin, and Washington that have pioneered innovative caregiver support initiatives. When completed, the strategy will chart a course for the U.S. to better support family caregivers in ways that truly address their needs. It will identify actions that communities, providers, governments, and others can take to recognize and support the family caregivers who put their own lives on hold to assist a broad cross-section of Americans every day.

Since the formation of the council, additional legislation has been passed that advances recognition and inclusion of family caregivers. The [MISSION Act of 2018](#), expanded access to the VA's PCAFC to caregivers of eligible veterans of all eras, in a phased approach. Previously, only caregivers of eligible veterans who incurred or aggravated a serious injury on or after September 11, 2001 were eligible for this Program. This expansion represented one of the largest federal investments to date in a comprehensive program to support caregivers.

Previous Efforts to Tabulate Federal Programs

An inventory of existing federal programs and initiatives to support family caregivers as authorized in the RAISE Act has never been undertaken. Two previous inventory efforts offer guidance on how to plan and begin such an undertaking. In 2007, Centers for Medicare & Medicaid Services (CMS) released a white paper, [CMS Support for Caregivers](#), that listed all CMS programs and initiatives that support caregivers. While its purpose was to serve as an education and outreach tool for organizations that work on behalf of caregivers, the document provided a model of an inventory of programs to support caregivers, in part because it was comprehensive. The document included the nine legal authorities under which CMS could support family caregivers, and separately listed all activities to support caregivers in the areas of information, respite care, assessment, training, direct payments to caregivers, and research. There was considerable variation in program scope within the document, ranging from multi-million dollar initiatives, such as the section 1915(c) HCBS waivers and/or section 1115(a) demonstrations within Medicaid, to more discrete efforts such as a series of quarterly conference calls.

In 2011, the Obama administration embarked on a much broader effort to create a comprehensive inventory of [all federal programs](#) and provide that information in one central website, [Performance.gov](#). Its creation was required by the 2010 [Government Performance and Results Modernization Act](#) (GPRAMA) in order to provide Congress and the public a clearer picture of the programs that exist across the federal government. In 2013, an initial inventory was released providing descriptions of 1,524 program submitted by 24 agencies.

In 2014, the [Government Accountability Office \(GAO\) reported](#) that initial effort had fallen short of fully realizing its original goal. One of the reasons cited for this shortfall was that in soliciting program information, the Office of Management and Budget (OMB) had allowed for significant discretion on the part of respondents which led to a variety of approaches for defining what constitutes a federal program and led to inconsistencies in the details collected. Those differences in definition and level of detail resulted to what the GAO called a "lack of comparability" within agencies and across programs included in the inventory.

Understanding the Challenge

In response to the requirements of the RAISE Act, in 2020, the council and staff at ACL embarked on an information-gathering effort to begin developing an inventory of federal programs and initiatives that provide some form of direct or indirect assistance to family caregivers.



While efforts to understand the needs of and to assist family caregivers exist across federal agencies (e.g., ACL, CMS, Department of Labor), strategic planning about how government can support family caregivers is conducted within specific agencies, which increases decentralization and information siloes and inhibits coordination and cross-cutting analysis across programs. The development of a federal inventory of programs to assist family caregivers would provide greater visibility into existing programs and facilitate efforts by the council to identify program gaps, recommend actions to close those gaps, and improve coordination across agencies. The council's hope is that in so doing, they will also improve outcomes for family caregivers and the people they support while achieving program efficiencies.

Information-Gathering Process

ACL staff reviewed both of these previous efforts in the planning phases of developing the inventory of caregiver programs. Noted lessons learned include the need for consistent definition of family caregiver, which does not exist at this time, and the importance of targeting respondents best situated within a given agency to provide accurate and comprehensive information.

Given the complexity and critical importance of this issue and the vast landscape of federal agencies, the council determined that it would begin its information-gathering efforts by surveying the agencies mentioned in the RAISE Act and those represented on the council. From there, it would seek referrals and recommendations to other agencies in the executive branch to expand the information collected. This report includes the information gathered as of May 2021. The council anticipates that the development of the inventory will be an iterative process that will proceed in parallel with the implementation of the National Family Caregiver Strategy, which includes recommendations about defining and measuring caregiving programs.

Council members from both the RAISE Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren Advisory Council representing federal agencies responded to a call for information from the ACL Administrator. Each federal council representative was responsible for surveying his or her home institution to gather specific knowledge important to caregivers and their families and communities, and the staff and organizations who care for those caregivers. Council members also provided referrals to agencies not represented on the council, such as the Treasury Department, to ensure a broad collection of information. When complete, the council will use this information to increase transparency and improve alignment of caregiving support efforts across the federal government while at the same time avoiding duplication of effort and the creation of gaps in service when developing the National Family Caregiving Strategy.

As of May 2021, the council had collected information from the following agencies:

- AmeriCorps
- Consumer Financial Protection Bureau
- U.S. Department of Education
- U.S. Department of Health and Human Services (10 operating divisions)
- U.S. Department of Labor
- U.S. Department of Veterans Affairs

In addition to receiving input from federal agencies, the council received recommendations of programs to include from the public, which were submitted through ACL's 2019 request for information (RFI) seeking information on the experiences of family caregivers. Some of those suggestions are included in this document. The RFI also yielded many comments that validated the need for a resource that lists all available programs to assist family caregivers. Multiple responses suggest that existing programs do not meet the diverse needs of family caregivers or the volume of the caregiving population. For example, RFI comments indicate that caregivers are not aware of existing programs or do not feel existing programs are flexible enough to meet their needs. Members of the council also suggested programs for inclusion and provided edits for this document.



Initial Findings

Within the responses from these agencies, as expected, there was considerable variability in how agencies defined support to caregivers, program scope, level of administration, services provided, and targeted consumers. *In fact, one of the main revelations of the inventory is that there does not exist across the federal government a definition of what a caregiver is, nor are there clear definitions of what constitutes a program, as the GAO previously noted.* Some agencies referred to collections of resources as “programs,” where others used the same term to describe multi-billion-dollar efforts that addressed a range of caregiver needs.

The inventory process identified 50 plus total programs, although not all federal agencies participated. Three programs funded by the federal government were identified as ones that are holistically caregiver-centered and provide an array of services for a wide range of caregiver needs:

- ACL with its National Family Caregiver Support Program and Lifespan Respite Care Program.
- The Veterans Health Administration (VHA)’s Caregiver Support Program.
- HHS’ Administration for Children and Families (ACF) Kinship Navigator Program.

However, because by Congressional mandate each of these programs is limited to a subset of the population linked to the mission of the agency, the reach of these programs is limited. In addition, despite identifying a range of programs that offer some level of support to family caregivers, in the initial review, the council was not able to assess or measure to what extent those programs met the existing needs of the nation’s millions of family caregivers.

Different congressional authorities and legislative priorities have created a piecemeal approach to various aspects of caregiving. There are no programs that cover the broad array of supports for caregivers of people with disabilities of all ages. In other ways, the piecemeal approach has led to overlaps between disparate programs. For example, six separate programs operated by three different federal agencies address—to some degree—the needs of rural caregivers. The programs, such as the Rural Health Care Services Outreach Program, a series of grants funded by the Health Resources and Services Administration (HRSA), tended to address isolation, much-needed improvements to care delivery, and access to timely, quality care in rural settings. However, it was not clear on initial review which of these efforts included practical resources that might benefit, for example, a rural caregiver in need of transportation to a medical appointment—an important challenge for rural caregivers. Nor were any programs identified in 2020 that addressed the pressing need among rural individuals for improved telecommunications and broadband access, and increased digital literacy.

In addition, several agencies identified person-centered initiatives and programs. An example of this is the Patient Listening Sessions offered by the U.S. Food and Drug Administration (FDA). Programs such as this are not aimed specifically at caregivers, but caregivers are important stakeholders who benefit from their existence. If those person-centered services were removed, it is likely that more tasks would fall to the family caregiver.

In sum, the council found that the federal government provides programs (inventory effort collected more than 50 program descriptions) that provide some level of support to family caregivers. However, this figure belies the fact that one of the most commonly cited concerns of family caregivers is the lack of consistent government support. This appears throughout the literature and in the ACL RFI, and reflects the experience of multiple council members and public participants in council deliberations. Moreover, the existing patchwork of family caregiver programs is not flexible and culturally sensitive enough to address the needs of diverse populations nor the size of the caregiving population. This was particularly evident in RFI comments indicating caregivers are not aware of existing programs or do not feel existing programs are flexible enough to meet their needs.

The programs identified during the information-gathering process were diverse in size, scope, and mission. There also appeared to be four root causes for the development and maintenance of federal caregiver support efforts:



- Caregiver specific funding was authorized or mandated by way of legislation.
- Caregiver support programming was developed because it was wrapped into a set of services and supports that addressed the needs of the given population.
- Caregiver support was an area of interest that was through specific funding lines as demonstration projects, or through research grants.
- Caregiver support education was considered so critical that the organization developed services or educational strategies within existing budget lines.

Because of these foundational disparities, the programs identified rarely appeared to be holistically caregiver-centered in their design. Rather, the support of the caregiver was often a secondary focus of the effort. For example, the programs administered by HHS focus on health care or social services, even though some services to caregivers are available. Programs administered by the Department of Education, focus, as one would expect, on childhood education. There does not appear to be a unifying set of definitions of caregiving or of ways of measuring caregiver needs and tracking efficacy. As previously noted, there is no consensus on the statistical prevalence of caregiving. This suggests that there are differing perspectives across federal agencies of the need for interventions to support family caregivers.

These disparities create dissonance between existing programs, which reduces the effectiveness of broad caregiver support efforts. A summary comparison of the list of submitted program descriptions against the five priority (recommendations) areas identified by the council and adopted in November 2020 reveal significant gaps in programs and initiatives that focus on increasing awareness of family caregiving and those that address its related financial challenges. At the same time, while there were a relatively robust number of programs that appeared to conduct research or engage in data collection about caregiving, there does not appear to be coordination across these efforts or a consistent mechanism for information sharing. Finally, while the greatest number of programs offered services and supports to assist caregivers, the anecdotal findings of the RFI suggest that those services are difficult to access and many caregivers do not know they exist, suggesting a need for a mechanism for national coordination of information about services and supports, similar to the Kinship Navigator programs, described here.

In addition, funding mechanisms also varied considerably, which can affect administrative flexibility. Some of the federal efforts, such as the National Family Caregiver Support Program, are funded by way of public law and legislative authority. Other organizations appear to have developed pathways within their operations to pursue supports and strategies that have been found to be important and effective within a unique population served by the agency or within of the area expertise of the agency. An example of this is the [National Family Support Technical Assistance Center](#) funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), which provides support to family and caregivers of children who experience serious mental illness and/or substance use disorders

Most of the programs identified were modest in size and funding. Only three agencies offered programs that focused specifically on the needs of the caregiver as a primary driver of program design:

- ACL with the NFCSP and the Lifespan Respite Care Program.
- The VHA's Caregiver Support Program.
- HHS' ACF Kinship Navigator Program.

Because by congressional mandate each of these programs is limited to a subset of the population linked to the mission of the agency—the reach of these programs is limited. Funding for these programs is also limited. This fragmentary and disparate approach creates missed opportunities for more comprehensive support that comes at significant risk to the ability of family caregivers to support their family members over time. It also hampers the ability to develop and evaluate best practices for caregiver support because most existing programs focus on populations defined by specific, but disparate factors such as disease (cancer caregiving), Medicaid status, age of the caregiver or person receiving care (National Family Caregiver Support Program). These categorizations limit the ability to collect data that reflects the true complexity and heterogeneity of family caregiver needs.



A significant limitation of the information-gathering process was the fact that even within specific agencies, not all programs were easily identifiable as direct or indirect sources of support to family caregivers. It quickly became clear to ACL staff that developing the inventory would necessarily be an iterative process as awareness increases across the federal government about systemic information gathering as a necessary step in developing programs that support family caregivers. For this reason, the Inventory of Federal Caregiver Support Programs and Initiatives will be updated over time with updates provided to the council.

Existing Federal Approaches to Assisting Caregivers

Over recent decades, a number of approaches have emerged to support family caregivers including direct support programs that address a range of caregiver needs, single service approaches where specialists offer interventions that fill specific caregiving gaps, training and education initiatives aimed at increasing confidence and efficacy among caregivers, and peer-to-peer interventions that include counseling, training, and respite. Often, successful efforts begin in communities or states, as either grass roots efforts or part of a demonstration project.

In fact, existing federal efforts to support caregivers were often an attempt to bring to scale successful approaches tested at the state and local levels. A proven example of this is the National Family Caregiver Support Program, which had its genesis in several successful state caregiver programs. Despite limited funding, since the passage of the National Family Caregiver Support Act in 2000, a growing body of federal programs and initiatives have emerged to coordinate and disseminate information, best practices, and services for family caregivers. Congress' call for a National Family Caregiving Strategy—which is to be informed by the development of an inventory of existing federal programs—is an important step in the realization of a vision where caregivers across the nation can receive the assistance they need in a coordinated and efficient manner.

Overarching Considerations of Effective Caregiver Support

While there are many ways to assist caregivers, the recognized first step involves understanding caregiver needs in relation to the care needs of the person receiving support. Without a systematic approach to assessing the overall needs of the family, developing a comprehensive system of support for the caregiver is compromised, which, in turn, exposes the family caregiver to negative consequence linked to the caregiving experience (e.g., burden, stress, depression, poorer than expected health outcomes).

Over the past two decades there have been increasing calls from professional societies, advocacy organizations, and consensus committees for a standardized, universally available assessment of the family caregiver as an important component of a person- and family-centered care planning process. Thus, the development of numerous approaches and tools focused on caregiver assessment have merged in recent years. Some are designed for specific populations. Others are designed to be a comprehensive assessment of a variety of caregiving situations. Two evidence-based approaches to caregiver assessment are 1) the [BRI Care Consultation](#) used with caregivers of adults with dementia and other conditions, and 2) a comprehensive caregiver assessment tool, the [Tailored Caregiver Assessment and Referral](#) (TCARE).

Caregiver assessments can take place in the home or a clinical setting—or in some cases over the phone or via telehealth. A typical assessment might involve a trained professional or peer caregiver asking the family caregiver—in a non-judgmental way—about:

- Their caregiving tasks.
- Their comfort level and confidence performing these tasks (including the use of or interest in using technologies related to caregiving).
- Their overall emotional and physical well-being.
- Their own goals.
- Their ability and willingness to continue to be a caregiver.
- The types of supports they feel would be most helpful to them.
- Their legal and financial needs.



- The levels of paid and unpaid support they currently have.
- Their basic eligibility for existing services and supports (level of impairment, household or individual income, VA status, etc.).

Caregiver Assessment: A Tool for Understanding What the Caregiver Needs

Caregiver assessment is a systematic process of gathering information about (1) the caregiver’s specific problems, needs, strengths, and resources; (2) the needs of the person receiving support; (3) the caregiver’s ability to help meet those needs; and (4) caregiver interactions or relationships with health care teams and/or LTSS systems. The findings of the assessment form the basis of a support plan tailored to the needs of the caregiver and can include care consultation, training, respite, and other supports (Feinberg & Houser, *Assessing Family Caregiver Needs: Policy and Practice Considerations*, 2021).

The answers to these questions form the basis of a culturally sensitive plan for helping the caregiver continue to provide support. Interventions could involve education and counseling, offering potential respite opportunities, soliciting other family members to assist with caregiving, role modeling caregiving for the caregiver, and fostering the idea that the family caregiver is not alone. As noted previously, caregiver assessments have the potential to improve caregivers’ understanding of their needs, as well as understand their ability to continue to provide support, and when implemented across populations, have the potential to provide meaningful meta-analysis about systemic caregiving needs, and to identify gaps in programming.

Comprehensive Direct Support Programs

Across the federal government, there are programs, supports, and other interventions designed to support family caregivers. One proven approach to directly supporting caregiving is with a model of programming that offers multiple, flexible services options that are responsive to caregiver needs as they change over time (Avison, et al., 2018). Typically, these models include information and/or training for caregivers, assistance with navigating services (including understanding options for supports), counseling and/or training of community mental health professionals to better understand and address caregiver-specific needs, and respite care. Other ancillary services may include employment assistance, transportation, or advice on accessing services and supports. These direct support models also can support indirect services and infrastructure development through research and policy development that leverages their work with family caregivers.

The federal government funds three specific programs that are structured to directly address a broad array of caregiver issues for eligible family caregivers:

- The [NFCSP](#), established in 2000 and operated by ACL, the NFCSP provides grants to states and territories that fund Area Agencies on Aging to provide a range of services that assist family and informal caregivers to care for their family members at home for as long as possible. Services to family caregivers include:
 - Information for caregivers about a range of supports, resources, and services available.
 - Assistance in gaining access to services that help connect caregivers with services offered by private, public, and voluntary agencies or through insurance.
 - Caregiver education/training, individual counseling, and support to help caregivers better manage their responsibilities and cope with the stress of caregiving.
 - Respite care provided by trained caregivers either delivered at home or at adult day care or other facilities, so that caregivers can rest or attend to their own needs.
 - Supplemental services such as transportation, home modifications, and medical or incontinence equipment.
- The [VA Caregiver Support Program](#) (CSP) offers an array of supports and services to family members and friends who care for veterans, including on-line courses, face-to-face classes, telephone support, and peer support. These services are offered in



addition to the support provided to families and caregivers across VA by clinicians as part of a veteran's care. Every VA medical center has dedicated Caregiver Support Program staff who assist with information and referrals to these programs. Many of the following programs are also available to veterans who serve as the family caregiver to a non-veteran:

- Six-week online workshop for caregivers of veterans of all eras, with text support.
- Caregiver self-care courses.
- Website and a Caregiver Support Line.
- Telephone education and support groups.
- Peer support.
- **Kinship Navigator Programs** are funded by the Administration for Children and Families (ACF). These services assist kin and grandparent caregivers in communities across the nation in learning about and accessing programs and resources to meet the needs of the children they are raising, to provide help for the family as a whole to safeguard stability, and to promote partnerships among public and private agencies. Kinship navigator programs are not intended to provide services; rather, they improve caregivers' knowledge of services and assist them in identifying and accessing the services they need (Child Welfare Information Gateway, 2019).

These federal programs are models that show promise for holistically supporting the needs of family caregivers. A [comprehensive evaluation of the NFCSP](#) conducted from 2016 to 2018, found that "caregiver use of the services made available by the NFCSP helped them continue in their role for longer periods, an important factor in delaying or preventing the institutionalization" (Avison, et al., 2018).

Meanwhile, in an evaluation of the suite of caregiver services offered at the Atlanta VA Health Care System, the caregiver support programming was found to be beneficial to caregivers through such mechanisms as increased knowledge of dementia, greater social support, increased self-efficacy to care for the veteran, behavior modification, and an emphasis on caregiver well-being (Biello, et al., 2019).

Kinship Navigators Help Kin and Grandparent Caregivers Navigate a Path to Success

Kinship navigator programs seek to provide information, offer referral, and follow-up services to grandparents and other relatives raising children to link them to the benefits and services that they or the children need. [SHARE New Mexico](#) is a successful example of an effective kinship navigation program embedded within a more comprehensive family caregiver program. SHARE serves as a "first stop" to connect caregivers with existing resources such as family support, trauma assistance, support groups, legal aid, benefits assistance, and community resources.

Positive outcomes for those receiving kinship navigator services include:

- **Safety:** Relative caregivers receiving navigator services achieved identified safety goals for their families.
- **Permanency:** Children in the care of relative caregivers receiving navigation services had higher rates of permanency through legal guardianship and reunification with parents.
- **Well-being:** Results showed that kinship navigator programs were successful at ameliorating the needs of grandfamilies (Generations United, 2020).

The significant challenge, as noted, relates to scalability. Each of these promising programs limit eligibility to specific caregiver populations—in this case, Veterans, adults and/or their caregivers, or grandparent caregivers. Millions of family caregivers do not fall into these groups and do not have access to a comprehensive direct support caregiver program. Instead, they are left to fashion their own support systems while juggling the needs of the family member they care for and their own well-being. It is worth noting that even within the programs, access is not



equally distributed. There are often lengthy waitlists for many of these programs and significant unmet need around the country for services for individuals who meet eligibility criteria.

Single-Service Approaches

An alternative to the wrap-around model of caregiver support is the use of stand-alone programs—such as respite care, counseling, or support groups—that address discrete caregiver needs. A key example of an effective single service is the [Lifespan Respite Care Program](#), which is administered by ACL. The program helps build and sustain “systems of accessible, community-based respite care for family caregivers of children and adults of all ages with special needs.”

This is important because respite has been found in several studies to improve family caregiver resilience, and benefit their physical and emotional health. One study found that respite can improve resilience in caregivers of people living with dementia, which is often a particularly intense form of caregiving, especially, when people are in the advanced stages of the illness (Robert & Struckmeyer, 2018).

Respite Care: An Essential Caregiver Support

While caregivers report significant emotional and spiritual rewards from the caregiving experience, they also experience physical and emotional issues as a result of the demands of their caregiving responsibilities. The concept of respite as a supportive service is based on the premise that giving caregivers a break from daily, ongoing caregiving responsibilities will benefit their physical and emotional health and enable them to provide caregiving support for longer. Despite the benefits, respite remains an underutilized support for family caregivers. To advance understanding of the value of respite, the ARCH National Respite Network and Resource Center convened a work group in 2015 to develop a research agenda for respite care. The work group defined the term “respite care” as:

“Respite is planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some measurable improvement in the well-being of the caregiver, care receiver, and/or family system.”

Single-service interventions, like respite care services, benefit from greater flexibility and adaptability to changing environments. However, many caregivers experience barriers to accessing these services. The COVID-19 pandemic has increased awareness among families of the need for respite at the same time that, due to risk of infection for both care providers and the people receiving support, many services have suspended operations. Recognizing the need for increased awareness of the value of respite and greater access to services, the council developed Recommendation 3.2, which specifically focuses on expanding use of respite care.

Training and Education

A significant body of research has shown that caregivers need education and information to be more successful in their roles. Family caregivers need trusted information on a range of topics from how to perform functions necessary to provide care (e.g., dressing changes, managing pain, etc.) to how to deal with behaviors (in the case of dementia) and managing stress and emotional challenges that can come with being a caregiver.

A successful example of the effectiveness of caregiver education and training at the federal level is ACL’s [Alzheimer’s Disease Programs Initiative](#) (ADPI). Caregivers of people living with dementia receive training to manage the complex emotions and grief associated with dementia and to manage challenging behaviors. ADPI is dedicated to meeting this challenge by developing what is known as “dementia capability” in states and expanding it in communities. This effort involves funding community-based projects that include training and education specifically for family caregivers of people living with dementia. The program seeks to expand



the network of local knowledge and support by training members of the surrounding community in how to recognize the signs of dementia and interact with people living with dementia.

To date, ADPI has trained a wide array of individuals including paid caregivers, social workers, attorneys, financial professionals, law enforcement, first responders, food service workers, and small business owners. Together, this expansion of community-wide understanding of the needs of people living with dementia and their caregivers provides a foundation for more effective systems of services and supports.

Training is not the only effective method of educating caregivers so they can be successful in their role. Outreach in the form of educational materials also plays an important role. The Consumer Financial Protection Bureau produces [Managing Someone Else's Money guides](#) for the millions of family caregivers who manage money or property. Since 2013, when the guides became available, more than 1,411,038 copies of the guides have been requested for distribution at libraries, community centers, social services providers, legal aid offices, and financial institutions.

Education and training is an area ripe for development because caregiver research has shown "that education and skills training can improve caregiver confidence in managing daily care challenges" (National Academies of Sciences, Engineering, and Medicine, 2016). Increased mastery can boost caregiver confidence, which in turn can lead to reductions in stress and perception of burden.

Peer-to-Peer Approaches

Peer support models pair individuals new to a caregiving situation with someone who has previous experience in the role. Nearly a third of family caregivers have been providing support for five or more years (AARP and National Alliance for Caregiving, 2020). These family caregivers have amassed significant knowledge and expertise that is different from the kinds of support formal systems offer. In many cases, these experienced family caregivers are ideally positioned to lend their perspectives and expertise to others with less experience in the role. Peer-to-peer supports can help to reduce reliance on the formal system; as such, it is effective for where there may not be many formal supports available.

For people with IDD the role of family is unique, and often central in the support and care provided across the lifespan. From 2012-2017, ACL funded the [Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities](#) to discover integrated, flexible, and innovative strategies for supporting the entire family, rather than focusing solely on formal services. One of the key approaches identified was peer-to-peer support. One of the reasons for this was that parents of individuals with IDD trying to identify and access appropriate services often find the systems of support complicated and overwhelming. Peer support enables families to navigate systems more effectively, learn from the experiences of other families, feel less alone, and gain hope, ideas, and information.

Caregiver peer support is not readily available in existing service delivery models. One notable federal exception is the [Caregiver Peer Support Mentoring Program](#) which is available as part of VA's Caregiver Support Programming.

Future Steps for the Federal Inventory

The inventory development process was made complex by the variability of existing programs and the fact that, in a number of cases, even within specific agencies, designated respondents were not fully aware of all efforts underway that supported or assisted family caregivers at their specific agency. It quickly became clear to the council and ACL staff that developing the inventory would necessarily be an iterative process, updated over time through an ongoing engagement with federal partners and regular dialogue with the council.



Inventory of Federal Caregiver Support Programs and Initiatives

AmeriCorps

AmeriCorps Seniors

PROGRAM NAME: Foster Grandparent Program

TARGET CAREGIVER POPULATION: Kinship Families and Grandfamilies (i.e., offers seniors age 55 and older opportunities to serve as mentors, tutors, and loving caregivers for socioeconomically disadvantaged children and youth from birth to 21 years of age).

URL(s): <https://americorps.gov/serve/fit-finder/americorps-seniors-foster-grandparent-program>

AUTHORITY: Domestic Volunteer Service Act of 1973, 45 CFR Part 2552 and § 2553.11.

SUMMARY: The AmeriCorps Seniors Foster Grandparent program is a community-based, direct services, volunteer program that provides critical community support to the nation's community organizations and their residents. AmeriCorps Seniors volunteers who serve as Foster Grandparents become one-on-one tutors, mentors, and friends to young people with exceptional needs, where they act as role models to reinforce important life values. In 2017, around 22,000 Foster Grandparent volunteers helped approximately 150,000 children through a nationwide network of organizations.

The Foster Grandparent program is an intergenerational program where volunteers have the sole mission to help strengthen the education and emotional development of children at risk of falling behind in school, many of whom are being raised by grandparents. As tutors and mentors, these non-relatives provide a consistent and stabilizing older adult presence in the lives of the children they serve. Also, many Foster Grandparent volunteers are also themselves, grandparents to young children. Grandparents are supported through the Foster Grandparent program as the program supports the educational and emotional development of some of the children being raised by their grandparents. This support falls under several strategic focus areas that include education, healthy futures, and veterans and military families who are also supported by the volunteers in this program.



PROGRAM NAME: The RSVP Program

TARGET CAREGIVER POPULATION: Family Caregivers; Kinship Families and Grandfamilies.

URL(s): <https://americorps.gov/serve/fit-finder/americorps-seniors-rsvp>

AUTHORITY: Domestic Volunteer Service Act of 1973, 45 CFR Part 2552 and § 2553.11.

SUMMARY: The RSVP program is a community-based, direct services, volunteer program that provides critical community support to the nation's community organizations and their residents.

In addition, grandparents receive support through the RSVP program through several focus areas that include education, economic opportunity, healthy futures, and veterans and military families. For example, RSVP volunteers help teach money management to those grandparents who might be challenged with developing family budgets and securing credit. They also help educate grandparents on issues around financial exploitation and avoiding frauds and scams. Additionally, in the education realm, RSVP volunteers also teach English to grandparents for whom English might be a second language.

Note: The RSVP program engages and models several health-related interventions in the ACL evidence exchange. These include:

- A Matter of Balance (older adult falls-prevention program).
- Chronic Disease Self-Management Program (intervention for improved management of chronic diseases).
- Seniors Reach (intervention for reduced isolation and depression).

PROGRAM NAME: Senior Companion Program

TARGET CAREGIVER POPULATION(S): Family Caregivers.

URL(s): <https://americorps.gov/serve/fit-finder/americorps-seniors-senior-companion-program>

AUTHORITY: Domestic Volunteer Service Act of 1973, 45 CFR Part 2551.

SUMMARY: AmeriCorps Seniors provides grants to qualified agencies and organizations for the purpose of engaging adults age 55 and over in meaningful volunteer service through the Senior Companion program.

The AmeriCorps Seniors Senior Companion program is a community-based, direct service, volunteer program that provides critical community support to the nation's community organizations and their residents. Since 1974, as a peer-to-peer program, Senior Companion volunteers have made a difference by providing assistance and friendship to adults who have difficulty with daily living tasks, such as shopping or paying bills. This assistance from Senior Companion volunteers helps their neighbors to retain their dignity and remain independent in their homes rather than having to move to more costly institutional care.

Additionally, Senior Companion volunteers provide respite and other services for family caregivers, allowing them time to conduct their own business and/or just to refresh from caregiver responsibilities.

One key difference between AmeriCorps Seniors and other volunteering opportunities is the provision of a small hourly stipend for volunteers who have incomes up to twice the poverty line. While most volunteers reported joining service for altruistic reasons, close to one-third had an underlying financial reason. The modest stipend provided by AmeriCorps Seniors helps remove the barriers to volunteering and ensures participants do not incur additional costs while serving.



Consumer Financial Protection Bureau (CFPB)

PROGRAM NAME: Office for Older Americans

TARGET CAREGIVER POPULATION(S): Family Caregivers, Kinship Families and Grandfamilies (also aging services providers, service coordinators, nursing home and assisted living administrators and staff, and patient advocates).

URL(s): <https://www.consumerfinance.gov/practitioner-resources/resources-for-older-adults/>

AUTHORITY: 12 U.S.C. § 5493(g). The CFPB, through its Office for Older Americans, is charged with developing initiatives designed to protect consumers, 62 and older, from unfair, deceptive, and abusive practices, and assist them with current and future financial choices.

SUMMARY: The CFPB, through its Office for Older Americans, is charged with developing initiatives designed to protect consumers, 62 and older, from unfair, deceptive, and abusive practices, and assist them with current and future financial choices. 12 U.S.C. § 5493(g). The Office for Older Americans engages in research, policy, and educational initiatives, designed to help protect older consumers from financial harm and help older consumers make sound financial decisions as they age.

Programs and initiatives for older adults and their caregivers are primarily focused on financial education and the prevention of elder financial exploitation. These programs and initiatives include:

Money Smart for Older Adults (MSOA)-Money Smart for Older Adults is a module-based fraud-prevention program that provides older adults and their caregivers with information and tips to help prevent common scams and other types of elder financial exploitation. A wide range of intermediaries from financial institutions to adult day care and community service providers use MSOA guides and presentations to improve and increase awareness in their own communities.

Managing Someone Else's Money (MSEM)-The Managing Someone Else's Money guides help financial caregivers, also called fiduciaries, understand their role, detect, and prevent financial exploitation, and access relevant social services. Each guide focuses on one of four different fiduciary roles: power of attorney, trustees, court-appointed guardians, and government fiduciaries. State-specific guides are also available for 10 states.

Fraud prevention placemats, handouts, and activity sheets-Free fraud prevention placemats, handouts, and activity sheets help older adults and their families recognize and avoid common scams. They can be used by meal delivery programs, faith-based organizations, financial institutions, senior centers, or other groups in a variety of ways.

Protecting Residents from Financial Exploitation: A guide for nursing homes & assisted living facilities-This guide helps congregate care administrators and staff protect residents from financial exploitation through prevention and early intervention. Caregivers and patient advocates can use the guide as a trustworthy reference for best practices in preventing financial exploitation in congregate care settings.

Single and bulk orders of copies of CFPB materials are available to the public through the Government Printing Office website at:

<https://pueblo.gpo.gov/CFPBPubs/CFPBPubs.php?NavCode=XA&CatID=28>



U.S. Department of Health and Human Services (HHS)

Administration for Children and Families (ACF)

PROGRAM NAME: Title IV-E Guardianship Assistance Program (GAP)

TARGET CAREGIVER POPULATION(S): Kinship Families and Grandfamilies (i.e., relatives who have assumed legal guardianship of eligible children that they previously cared for as foster parents). As of November 2020, 38 states, the District of Columbia, Puerto Rico, the Virgin Islands, and several tribes participate in the program

URL(s): <https://www.acf.hhs.gov/cb/resource/title-iv-e-guardianship-assistance>

AUTHORITY: P.L. 110-351; Title IV-E of the Social Security Act; Section 471(a)(28), Section 473(d) of the Social Security Act (the Act) establishes eligibility and other requirements for the title IV-E GAP. Federal financial participation (FFP) using the applicable Federal medical assistance percentage is available for kinship guardianship assistance payments pursuant to section 474(a)(5) of the Act.

SUMMARY: The Children's Bureau partners with federal, state, tribal, and local agencies to improve the overall health and well-being of our nation's children and families. The Children's Bureau provides support and guidance to programs that focus on:

- **Strengthening families** and preventing child abuse and neglect.
- **Protecting children** when abuse or neglect has occurred.
- Ensuring that every child and youth has a **permanent family** or family connection.

The Guardianship Assistance Program provides federal financial participation to states, Indian tribes, tribal organizations, and tribal consortia (tribes) who, as part of their approved title IV-E Foster Care and Permanency program, opt to provide guardianship assistance payments to relatives who have assumed legal guardianship of eligible children that they previously cared for as foster parents.

Guardianship assistance is intended to prevent inappropriately long stays in foster care and to promote the healthy development of children through increased safety, permanency, and well-being. Title IV-E agencies must negotiate and enter into a written, binding kinship guardianship assistance agreement with the prospective relative guardian, and provide the prospective relative guardian.

Beneficiaries include children eligible for Title IV-E foster care maintenance 1) residing for at least 6 months in the home of the prospective relative guardian; 2) state or tribe determined permanency options of home or adoption are not appropriate; 3) child demonstrates strong attachment to guardian and prospective guardian commitment; 4) child age 14 and older consulted regarding kinship guardianship arrangement.

PROGRAM NAME: Kinship Navigator Program

TARGET CAREGIVER POPULATION(S): Kinship Families and Grandfamilies (i.e., grandparents, relatives and kin raising children in their homes, either through foster care or outside the child welfare system).

The Children's Bureau partners with federal, state, tribal, and local agencies to improve the overall health and well-being of our nation's children and families. The Children's Bureau provides support and guidance to programs that focus on:

- **Strengthening families** and preventing child abuse and neglect.
- **Protecting children** when abuse or neglect has occurred.
- Ensuring that every child and youth has a **permanent family** or family connection).



URL(s): State Kinship Care Contacts available at:
<https://www.childwelfare.gov/topics/outofhome/kinship/>

Title IV-E Prevention Services Clearinghouse: <https://preventionservices.abtsites.com/>

AUTHORITY: (PL) 115 -123 Bipartisan Budget Act - Title VII Family First Prevention Services Act (amended Title IV-E of the Social Security Act).

SUMMARY: Kinship Navigator Programs assist kinship caregivers in learning about, finding, and using programs and services to meet the needs of the children they are raising and their own needs. They are intended to avoid duplication or fragmentation of services and to promote effective partnerships among public and private agencies (including 2-1-1/3-1-1 information systems, and ombudsman support) to ensure kinship caregiver families are served and connected appropriately. They are intended to be planned and operated in consultation with kinship caregivers and organizations representing them, youth raised by kinship caregivers, relevant government agencies, and relevant community-based or faith-based organizations. Kinship navigators establish information and referral systems that link kinship caregivers, kinship support group facilitators, and kinship service providers to each other, eligibility and enrollment information for federal, state, and local benefits, and relevant legal assistance. Kinship Navigator programs promote partnership between public and private agencies and others to increase knowledge around the needs of kinship care families and others who foster children in foster care under the state.

PROGRAM NAME: Administration for Native Americans (ANA)

TARGET CAREGIVER POPULATION(S): Family Caregivers; Kinship Families and Grandfamilies. All Native Americans, including federally recognized tribes, American Indian and Alaska Native organizations, Native Hawaiian organizations, and Native populations throughout the Pacific Basin (including American Samoa, Guam, and the Commonwealth of the Northern Mariana Islands).

URL(s): <https://www.acf.hhs.gov/ana>

AUTHORITY: Section 803(a) of the Native American Programs Act of 1974 (NAPA), 42 U.S.C. 2991b.

SUMMARY: The Administration for Native Americans (ANA) is a program office within the Department of Health and Human Services' Administration for Children and Families. ANA promotes self-sufficiency for Native Americans by providing discretionary grant funding for community-based projects, and training and technical assistance to eligible tribes and Native organizations.

The Administration for Native Americans (ANA) funds community-based projects under the Social and Economic Development Strategies (SEDS) program. Focus areas include:

- Social Development: Projects that develop and implement culturally appropriate strategies to meet the social service needs and well-being of Native Americans.
 - Addressing Mental Health.
 - Community Health.
 - Native Arts and Culture.
 - Nutrition and Fitness.
 - People with Disabilities and Community Living.
 - Public Safety and Security.
 - Strengthening Families and Parents.
 - Substance Abuse, Smoking, and Vaping.
- Economic Development: Projects that promote the creation of a sustainable local economy to enhance the economic independence of Native people.
 - Economic Stability.
 - Food Sovereignty.
 - Native Traditional Farming.
 - Opportunity Zones.



The purpose of the SEDS and SEDS-Alaska (SEDS-AK) program is to promote social and economic self-sufficiency for American Indians, Alaska Natives, Native Hawaiians, and Native American Pacific Islanders from American Samoa, Guam, and the Commonwealth of the Northern Mariana Islands. The SEDS and SEDS-AK programs support the principle that social and economic development are inter-related and essential for the development of thriving Native communities. SEDS and SEDS-AK projects focus on one or more of the following three inter-related concepts that form a foundation for self-sufficiency: (1) social development that supports local access to, control of, and coordination with programs and services that safeguard the health, well-being, and culture of Native peoples; (2) economic development that fosters the development of stable, diversified local economies and economic activities that provide jobs and business opportunities that promote economic well-being and self-sufficiency in Native American communities; and (3) governance that assists tribes, Native organizations and Alaska Native village governments to increase their ability to enhance their administrative infrastructure and capacity to develop and enforce laws, regulations, codes, and policies that reflect and promote the interests of community members.

Administration for Community Living (ACL)

PROGRAM NAME: ACL-Funded Resource Centers

TARGET CAREGIVER POPULATION(S): Family Caregivers; Kinship Families and Grandfamilies.

URL: <https://acl.gov/programs/strengthening-aging-and-disability-networks/national-resource-centers>.

AUTHORITY: Developmental Disabilities Act; Older Americans Act; Workforce Innovation and Opportunity Act; Help America Vote Act; Public Health Service Act; Health Insurance Portability and Accountability Act (HIPAA); Medicare Improvements for Patients and Providers Act (MIPPA); Elder Justice Act.

SUMMARY: ACL's numerous resource centers provide information primarily for professionals and therefore offer indirect support to family caregivers. However, several also offer consumer information directly to family caregivers.

- Aging Network Business Practice, Planning and Program Development.
- Community Innovations for Aging in Place (CIAIP) Technical Assistance Center.
- Eldercare Locator.
- Lifespan Respite Technical Assistance Center.
- National Aging Information and Referral (I&R) Support Center.
- National Older Adults Equity Collaborative
- National Alzheimer's and Dementia Resource Center.
- National Alzheimer's Call Center.
- National Center for Benefits Outreach and Enrollment.
- National Center on Elder Abuse
- National Center on Law and Elder Rights
- National Center on Elder Abuse: National Indigenous Elder Justice Initiative
- National Clearinghouse for Long-term Care Information
- National Consumer Protection Technical Resource Center
- National Resource Center on Women and Retirement Planning
- National Falls Prevention Resource Center
- National Long-Term Care Ombudsmen Resource Center
- National Pension Assistance Resource Center
- National Resource Center on Chronic Disease Self-Management Education Programs
- National Resource Center on Lesbian, Gay, Bisexual, and Transgender (LGBT) Aging
- National Resource Center on Nutrition and Aging
- National Resource Centers on Native American Elders
- Senior Medicare Patrol National Resource Center
- State Health Insurance Assistance Program (SHIP) National Technical Assistance Center



- UCEDD Resource Center

PROGRAM NAME: Aging and Disability Evidence-Based Programs and Practices

TARGET CAREGIVER POPULATION(S): Family Caregivers.

URL: <https://acl.gov/programs/strengthening-aging-and-disability-networks/aging-and-disability-evidence-based-programs>.

AUTHORITY: Developmental Disabilities Act; Older Americans Act; Workforce Innovation and Opportunity Act; Help America Vote Act; Public Health Service Act; Health Insurance Portability and Accountability Act (HIPAA); Medicare Improvements for Patients and Providers Act (MIPPA); Elder Justice Act.

SUMMARY: The purpose of the Aging and Disability Evidence-Based Programs and Practices is to help the public learn more about available evidence-based programs and practices in the areas of aging and disability, and to determine which of these may best meet their needs. The identified programs and practices address health and wellness, long-term services and supports (LTSS), caregiver and family support, and mental health promotion.

ACL's Administration on Aging

PROGRAM NAME: National Family Caregiver Support Program

TARGET CAREGIVER POPULATION(S): Family Caregivers, Kinship Families and Grandfamilies.

URL: <https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>

AUTHORITY: Section 371 of the Older Americans Act of 1965, as amended, Title IIIIE.

SUMMARY: Established in 2000, the NFCSP provides grants to states and territories, based on their share of the population age 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible. Eligible caregivers include: adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older; adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer's disease and related disorders; older relatives, not parents, age 55 and older providing care to children under the age of 18; and older relatives, including parents, age 55 and older providing care to adults age 18-59 with disabilities. NFCSP grantees provide five types of services: information to caregivers about available services; assistance to caregivers in gaining access to the services; individual counseling, organization of support groups, and caregiver training; respite care; and supplemental services, on a limited basis.

These services work in conjunction with other state and community-based services to provide a coordinated set of supports. Studies have shown that these services can reduce caregiver depression, anxiety, and stress as well as enable caregivers to provide care longer, thereby avoiding or delaying the need for costly institutional care.

PROGRAM NAME: Services for Native Americans (Title VI of the Older Americans Act)

TARGET CAREGIVER POPULATION(S): Family Caregivers; Kinship Families and Grandfamilies.

URL: <https://olderindians.acl.gov/>

AUTHORITY: In 1978, the OAA was amended to include Title VI which established programs for the provision of nutrition and supportive services for Native Americans (American Indians, Alaska Natives, and Native Hawaiians). The program has since expanded to include caregiver



support services. Eligible tribal organizations receive grants in support of the delivery of home and community-based supportive services for their elders, including nutrition services and support for family and informal caregivers.

SUMMARY: Programs provide grants to eligible tribal organizations to promote the delivery of home and community-based supportive services, including nutrition services and support for family and informal caregivers, to Native American, Alaskan Native, and Native Hawaiian elders. These programs, which help to reduce the need for costly institutional care and medical interventions, are responsive to the cultural diversity of Native American communities and represent an important part of the communities' comprehensive services.

Grants assist American Indian, Alaskan Native, and Native Hawaiian families caring for older relatives with chronic illness or disability, and grandparents caring for grandchildren. The program offers a variety of services that meet a range of caregiver needs, including information and outreach, access assistance, individual counseling, support groups and training, respite care, and other supplemental services.

Tribal organizations coordinate with other programs, including the Volunteers in Service to America (VISTA) program, to help support and create sustainable caregiver programs in Native American communities (many of which are geographically isolated). A core value of the Native American Caregiver Support Services, as expressed by tribal leaders, is that the program should not replace the tradition of families caring for their elders. Rather, it provides support that strengthens the family's caregiver role.

PROGRAM NAME: Alzheimer's Disease Programs Initiative (ADPI)

TARGET CAREGIVER POPULATION(S): Family Caregivers.

URL: <https://acl.gov/programs/support-people-alzheimers-disease/support-people-dementia-including-alzheimers-disease>

AUTHORITY: Titles II and IV of the Older Americans Act.

SUMMARY: In 1992, Congress created the Alzheimer's Disease Supportive Services Program (ADSSP) to support state efforts to expand the availability of community-level supportive services for persons with Alzheimer's disease and related dementias (ADRD). In 1998, Congress transferred the administration of the program to ACL. Between 2008 and 2017, ACL funded 108 ADSSP projects across the nation. In 2020, ACL publicized the Alzheimer's Disease Programs Initiative, to provide funding to support and promote the development and expansion of dementia-capable HCBS systems. The dementia-capable systems resulting from program activities are expected to provide quality, person-centered services and supports that help people living with dementia and their caregivers remain independent and safe in their communities.

PROGRAM NAME: Lifespan Respite Care Program

TARGET CAREGIVER POPULATION(S): Family Caregivers.

URL: <https://acl.gov/programs/support-caregivers/lifespan-respite-care-program>

AUTHORITY: Title XXIX of the Public Health Service Act (42 U.S.C 201). Eligible agencies are those administering the state's program under the Older Americans Act of 1965 or Title XIX of the Social Security Act (Medicaid), or those designated by a governor to administer the state's program under this title.

SUMMARY: Congress authorized the Lifespan Respite Care Program in 2006 under Title XXIX of the Public Health Service Act (42 U.S.C 201). Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with disabilities. As of 2017, competitive grants of up to \$200,000 each were awarded to eligible agencies in 37 states and the District of Columbia. Participating states have developed or built upon respite infrastructures to enhance or improve



access to and receipt of respite services, and they are focusing on providing gap-filling respite services to family caregivers and working with ACL to develop program performance and outcome measures.

PROGRAM NAME: RAISE Family Caregiving Advisory Council

TARGET CAREGIVER POPULATION(S): Family Caregivers.

URL: <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>

AUTHORITY: P.L. 115–119.

SUMMARY: The Recognize, Assist, Include, Support, and Encourage (RAISE) Family Caregivers Act, which became law on January 22, 2018, directs the Secretary of Health and Human Services (HHS) to develop a National Family Caregiving Strategy. The strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers. To support the development and execution of the strategy, the RAISE Act also directs the establishment of the Family Caregiving Advisory Council. The council is charged with providing recommendations to the Secretary of HHS on effective models of both family caregiving and support to family caregivers, as well as improving coordination across federal government programs.

PROGRAM NAME: Advisory Council to Support Grandparents Raising Grandchildren

TARGET CAREGIVER POPULATION(S): Kinship Families and Grandfamilies.

URL: <https://acl.gov/programs/support-caregivers/supporting-grandparents-raising-grandchildren-0>

AUTHORITY: P.L. 115–196.

SUMMARY: Supporting Grandparents Raising Grandchildren Act established the Advisory Council to Support Grandparents Raising Grandchildren. The Advisory Council identifies, promotes, coordinates, and disseminates to the public information, resources, and the best practices available to help grandparents and other older relatives both meet the needs of the children in their care and maintain their own physical and mental health and emotional well-being.

ACL's Administration on Disabilities

PROGRAM NAME: Centers for Independent Living

TARGET CAREGIVER POPULATION(S): Family Caregivers.

URL: <https://acl.gov/programs/aging-and-disability-networks/centers-independent-living>

AUTHORITY: Title VII Part C Section 721 of the Rehabilitation Act of 1973, as amended, Section 725 of the Rehab Act, Workforce Innovation and Opportunity Act of 2014, 29 U.S.C. 32.

SUMMARY: The Centers for Independent Living (CILs) program provides 354 discretionary grants to CILs, which are consumer-controlled, community-based, cross-disability, nonresidential, private nonprofit agencies that provide independent living services. At a minimum, centers funded by the program are required to: provide information and referral, independent living skills training, peer counseling, individual and systems advocacy, and services that facilitate transition from nursing homes and other institutions to the community; provide assistance to those at risk of entering institutions; and facilitate transition of youth to postsecondary life. Individual CIL projects may also provide services to support caregivers.

PROGRAM NAME: Supporting Families Communities of Practice

TARGET CAREGIVER POPULATION(S): Family Caregivers.



URL: <http://supportstofamilies.org/>

AUTHORITY: N/A.

SUMMARY: For people with intellectual and developmental disabilities, the role of family is unique, and often central in the support and care provided across the lifespan. From 2012-2017, ACL funded the Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities to discover integrated, flexible, and innovative strategies for supporting the entire family, rather than focusing solely on formal services. One of the key approaches identified was peer-to-peer support. One of the reasons for this was that parents of individuals with IDD trying to identify and access appropriate services often find the systems of support complicated and overwhelming. Peer support enables families to navigate systems more effectively, learn from the experiences of other families, feel less alone, and gain hope, ideas, and information. An additional tool developed was the Charting the LifeCourse framework to help individuals with disabilities and families at any age or stage of life develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. A series of LifeCourse education and outreach materials are available at

https://www.myorderdesk.com/Catalog/?Provider_ID=1166751.

PROGRAM NAME: University Centers for Excellence in Developmental Disabilities Education, Research & Service

TARGET CAREGIVER POPULATION(S): Family Caregivers.

URL: <https://acl.gov/programs/aging-and-disability-networks/national-network-university>

AUTHORITY: Section 151(a) of the DD Act of 2000.

SUMMARY: University Centers for Excellence in Developmental Disabilities Education, Research & Service (UCEDDs) are a nationwide network of independent but interlinked centers, representing an expansive national resource for addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families. UCEDDs support activities that address a range of issues, from prevention and early intervention to supported employment. UCEDD activities also focus on supporting families and caregivers of individuals with developmental disabilities. Specific services and resources available through UCEDDs may vary, but many offer a variety of resources for families and caregivers, including education, training, skill building, planning, service coordination and referral, home modifications, assistive technology, and research.

ACL's Center for Innovation and Partnership

PROGRAM NAME: Aging and Disability Resource Centers/No Wrong Door

TARGET CAREGIVER POPULATION(S): Family Caregivers.

URL: <https://acl.gov/programs/aging-and-disability-networks/aging-and-disability-resource-centers>

AUTHORITY: N/A.

SUMMARY: Aging and Disability Resource Centers (ADRCs) across the country seek to address the frustrations many older adults, people with disabilities, and family members experience when trying to learn about and access long-term services and supports.

ADRCs raise visibility about the full range of available options; provide objective information, advice, counseling, and assistance; empower people to make informed decisions about their long-term services and supports; and help people access public and private programs. ADRCs provide unbiased, reliable information and counseling to people with all levels of income.



ADRCs are an important part of the No Wrong Door (NWD) system model. A collaboration between ACL, CMS, and the VHA, the NWD initiative supports states working to streamline access to long-term services and supports for older adults, people with disabilities, and their families. NWD systems simplify access to LTSS and are a key component of LTSS systems reform.

NWD systems provide information and assistance not only to individuals needing either public or private resources, but also to professionals seeking assistance on behalf of their clients, and to individuals planning for their future long-term care needs. NWD systems also serve as the entry point to publicly administered long-term supports, including those funded under Medicaid, the Older Americans Act, Veterans Health Administration, and state revenue programs.

PROGRAM NAME: Veterans-Directed Care Program (formerly known as the VD-HCBS Program)

TARGET CAREGIVER POPULATION(S): Family Caregivers, Veterans.

URL: <https://acl.gov/programs/veteran-directed-home-and-community-based-services/veteran-directed-home-community-based>

AUTHORITY: N/A.

SUMMARY: In 2008, ACL, on behalf of HHS, began a partnership with Veterans Health Administration (VHA) to serve veterans of all ages at risk of nursing home placement through the Veteran Directed Care Program [formerly known as Veteran-Directed Home and Community-Based Services (HCBS)]. The purpose of the program is to have an LTSS system that is person centered and consumer directed, and that helps people at risk of institutionalization to continue to live at home and engage in community life. Through the program, the VHA increases access to HCBS to serve the growing demand of veterans who prefer independence at home over living in a nursing facility.

ACL's National Institute on Disability, Independent Living, and Rehabilitation Research

PROGRAM NAME: Rehabilitation Research and Training Center Programs

TARGET CAREGIVER POPULATION(S): Family Caregivers.

URL: <https://acl.gov/programs/research-and-development/rehabilitation-research-and-training>

AUTHORITY Title 29, Chapter 16, Subchapter II, Section 762 of the Rehabilitation Act of 1973, as amended.

SUMMARY: The Rehabilitation Research and Training Center programs are funded through ACL's National Institute on Disability, Independent Living, and Rehabilitation Research. The programs conduct coordinated, integrated, and advanced programs of research, training, and information dissemination to improve rehabilitation methodology and service delivery systems; improve health and functioning; and promote employment, independent living, family support, and economic and social self-sufficiency for individuals with disabilities.



Centers for Disease Control and Prevention (CDC)

National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control

PROGRAM NAME: Resources for Caregivers of Cancer Survivors

TARGET CAREGIVER POPULATION(S): Family Caregivers (including caregivers of cancer patients and survivors).

URL: <https://www.cdc.gov/cancer/survivors/caregivers/index.htm>

AUTHORITY: Public Health Service Act – 42 U.S.C. § 241(a) and 247b (k) (2)

SUMMARY: CDC's [Division of Cancer Prevention and Control \(DCPC\)](#) works to help cancer survivors live longer, healthier lives and provide resources for caregivers of cancer patients and survivors.

CDC works with public, non-profit, and private partners to develop and implement ways to help the growing number of cancer survivors and their caregivers in the United States. Additionally, CDC conducts research and surveillance and develops programs to assess the needs of cancer survivors and caregivers. For example, CDC's [National Comprehensive Cancer Control Program \(NCCCP\)](#) encourages its awardees to pay special attention to the needs of cancer survivors and their families in their communities. CDC also funds the National Cancer Survivorship Resource Center, a collaboration between the American Cancer Society and the George Washington University Cancer Institute. The center develops and distributes a broad range of informational materials, including [Tools for Cancer Survivors and Caregivers](#).

CDC also provides helpful tips and online resources that offer [Advice for Caregivers of Cancer Survivors](#) including information regarding [Caring for Yourself](#), [Helping Cancer Patients and Survivors Stay Physically Healthy](#), and [Helping Cancer Patients and Survivors Stay Mentally and Emotionally Healthy](#).

National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health

PROGRAM NAME: Alzheimer's Disease and Healthy Aging Program (AD+HAP)

TARGET CAREGIVER POPULATION(S): Family Caregivers (Including people living with Alzheimer's disease and related dementias, informal or unpaid caregivers of family or friends, and organizations or programs serving older adults and caregivers).

URL: <https://www.cdc.gov/aging/about/index.htm#:~:text=The%20Alzheimer's%20Disease%20and%20Healthy,for%20people%2065%20and%20older>

AUTHORITY: The Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act was signed into law on December 31, 2018 (P.L. 115-406) and amends the Public Health Service Act (Section 398A; 42 U.S.C. 280c-3-4).

SUMMARY: The Alzheimer's Disease and Healthy Aging Program, through BOLD and the Healthy Brain Initiative, works to support people living with Alzheimer's disease and related dementias, informal or unpaid caregivers of family or friends, and organizations or programs serving older adults and caregivers, using the public health approach, emphasizing policy, systems, and environments. This is done through a variety of programs and initiatives, described below.

Healthy Brain Initiative & BOLD: The Healthy Brain Initiative [Road Map Series](#) has a strong emphasis on [caregiving](#) and [tribal communities](#). AD+HAP worked with tribal communities and



partners to create a variety of [resources](#) for Indian Country. The third *Healthy Brain Initiative Road Map for State and Local Public Health* was released in late 2018 by AD+HAP and the Alzheimer's Association, identifying 25 actions for public health professionals related to cognitive health, including cognitive impairment and caregiving for persons with cognitive impairment through 2023. In 2019, the first *Road Map for Indian Country* was released, identifying eight priority actions for Indian Country.

AD+HAP worked with the National Council for Urban Indian Adults to create wisdom keeper [videos](#) specific to Indian Country for people with dementias and their caregivers. AD+HAP partnered with the Association of State and Territorial Health Officials (ASTHO) to develop culturally sensitive materials to educate and empower tribes and tribal populations about brain health and caregiving. The materials focus on cardiovascular risk factors related to brain health and caregiving issues for tribal communities. Additionally, AD+HAP developed an infographic describing subjective cognitive decline and related functional limitations and caregiving on American Indian/Alaska Native adults in order to educate stakeholders and policy makers on brain health in Indian Country. These are available in both English and Spanish.

Additionally, AD+HAP has developed a series of 5 Issue Maps that highlight specific sets of Road Map actions related to caregiving, risk reduction, early detection of Alzheimer's disease and related dementias, and the education of health professionals. The associated planning tool was developed to guide state and local public health professionals through quick steps in selected Road Map items and getting started with implementation in their jurisdictions. Two podcasts were also produced discussing the updated *Road Map*.

The BOLD Infrastructure for Alzheimer's Act was passed into law on December 31, 2018 (P.L. 115-406) and amends the Public Health Service Act (Section 398A; 42 U.S.C. 280c-3-4). It is designed to facilitate the translation of findings into public health practice. The activities outlined in BOLD are designed to create a uniform national public health infrastructure with a focus on issues such as increasing early detection and diagnosis, risk reduction, prevention of avoidable hospitalizations, and supporting dementia caregiving. It is designed to promote implementation of AD+HAP's *Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map* and the *Healthy Brain Initiative Road Map for Indian Country*.

Through [BOLD](#), AD+HAP funds one Public Health Center of Excellence (PHCOE) on Dementia Caregiving to focus on public health and systematic approaches to support spouses, partners, adult children, and other relatives and friends providing informal or unpaid help to people living with dementia. The first BOLD Public Health Centers of Excellence for Dementia Caregiving, which is a five-year award, was awarded in September 2020 to the University of Minnesota.

Additionally, through BOLD, AD+HAP funded 16 state, local, and tribal cooperative agreements with public health departments, and 2 additional BOLD Public Health Centers of Excellence on Dementia Risk Reduction and Diagnosis of Dementia. These recipients will increase education of public health officials and others on brain health, promote risk reduction, early detection and preventing avoidable hospitalizations, decreasing health disparities, and supporting caregiving and planning for people living with the disease.

BRFSS Data and Dissemination: AD+HAP collects and reports data on caregiving as part of public health surveillance efforts. Currently, the program uses the Behavioral Risk Factor Surveillance System ([BRFSS](#)) state-based survey to collect data on caregivers in states administering the [optional Caregiving module](#) each year. Data and knowledge gathered from this telephone survey surveillance effort are then reported to public health professionals and the public in a variety of ways. AD+HAP curates an online, customizable [data portal](#) that provides information regarding caregiving at various levels for different populations (e.g., national, state, race/ethnicity, gender, LGBT, veteran, and rural). AD+HAP authors and co-authors caregiving-focused scientific journal [articles](#) using these and other data.

The [State of Aging and Health in America: Data Brief Series](#) are topic-specific documents focusing on public health issues related to older adults, developed by AD+HAP and the National Association of Chronic Disease Directors. These briefs provide public health professionals with



the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity, which can be useful for states and other stakeholders in making informed decisions and policies related to these issues.

Data and resources are disseminated on the program's website and through data-focused products in English and Spanish such as state and population specific [infographics](#), [podcasts and videos](#) titled "Aging and Health Matters," social media posts, an electronic newsletter to more than 67,000 subscribers, data [briefs](#), and scientific presentations to partner organizations and at professional society meetings (e.g., The Gerontological Society of America).

Resources for Caregivers: AD+HAP supports unpaid caregivers of older adults through other information and online resources. They provide a downloadable, fillable [Care Plan](#) (in English and Spanish) to help caregivers balance their own life with the care they are providing. Care plans can reduce emergency room visits, hospitalizations, and improve overall medical management for people with a chronic health condition, like Alzheimer's disease and related dementias, resulting in better quality of life for all care recipients.

AD+HAP has developed a series of [web features](#) and [podcasts](#) on topics including helping people with Alzheimer's disease and related dementias and their caregivers stay physically active, care plans for older adults and their caregivers, and the health of caregivers.

They created a 30-second [animated caregiving video](#) to encourage caregivers to care for themselves and thus provide better care to their family member or friend. They have a variety of web content with [information for caregivers](#) of persons with disabilities in English and Spanish. They provide the [REACH OUT Caregiving Implementation Guide](#), providing a step-by-step approach to implementing REACH OUT, an evidence-based caregiver support program.

Emergency Preparedness: AD+HAP provides Emergency Preparedness information for caregivers of older adults and people with dementia. Additionally, AD+HAP connects users to CDC's [COVID-19](#) information and guidance for older adults and their caregivers.

Centers for Medicare & Medicaid Services (CMS)

PROGRAM NAME: Medicaid Program

TARGET CAREGIVER POPULATION(S): Family Caregivers; Kinship Families and Grandfamilies.

URL(s): <https://Medicaid.gov>

AUTHORITY: N/A.

SUMMARY: The Medicaid program provides significant funding for long-term services and supports (LTSS), which include home, community, and institutional care. Medicaid-funded home and community-based services (HCBS) are optional services that states may choose to offer to beneficiaries with identified needs, to facilitate their continued residence in the community and to better their health outcomes. HCBS can be authorized under several Medicaid authorities.

Section 1915(c) waiver programs have been in existence since the early 1980s and provide home and community-based services to individuals who otherwise would require services in an institution (a nursing facility, hospital, or intermediate care facility for individuals with intellectual disabilities). While respite care is often the most well-known service that provides relief to caregivers (and respite may be provided under the waiver), many other services can assist caregivers in their daily efforts to provide care to loved ones. At the state's discretion, waiver services can also include personal care services, case management, assistive technology, home modifications, day habilitation, and other services that can alleviate strain on caregivers. We further note that states can opt to fund family members who are caregivers as Medicaid providers.



Section 1915(i) programs are operated under the Medicaid state plan, and can provide, at state option, the same services available under 1915(c) waivers. The difference between these two programs is the population covered under each authority. The state constructs “needs-based criteria” to determine functional eligibility criteria for the program. Within statutory and regulatory parameters, states have discretion to determine those criteria. This authority can therefore be helpful to a broader array of Medicaid beneficiaries, including individuals with mental health or substance use disorder needs.

Section 1915(k) authorizes the Community First Choice state plan option, which also targets individuals who require an institutional level of care. Enhanced federal funding (a 6 percentage point increase in federal matching payments to states for service expenditures) is available for covered services. If a state elects to provide Community First Choice, the state must provide all of the following services:

- (1) Assistance with ADLs, IADLs, and [health-related tasks](#) through hands-on assistance, supervision, and/or cueing.
- (2) Acquisition, maintenance, and enhancement of skills necessary for the [individual](#) to accomplish ADLs, IADLs, and [health-related tasks](#).
- (3) Backup systems or mechanisms to ensure continuity of services and supports, as defined in [§ 441.505](#) of this subpart.
- (4) Voluntary training on how to select, manage and dismiss attendants.

At state option, benefits can also include purchases for items that are linked to an assessed need or goal in the individual’s person-centered plan. These services and supports include, but are not limited to expenditures that increase a beneficiary’s independence or substitute for human assistance, such as a microwave, when such a purchase meets an identified need and when Medicaid would have paid for the human assistance. States may also choose to allow expenditures for transition costs such as deposits for rent or utilities, purchasing bedding, basic kitchen supplies, and other necessities required for an individual’s transition to a home and community-based setting from a Medicaid funded institutional setting.

Person-centered planning requires that the independent assessment of the individual receiving HCBS and the individual’s person-centered service-plan (PCSP) adequately document reliance on unpaid caregivers to implement any elements of the plan, including the number of hours and intensity of supports. For 1915(c), under 42 CFR 441.301(c)(2)(v), for 1915(i) under 42 CFR 441.441.725(b)(5), and for 1915(k) under 42 CFR 441.540(b)(5), states are required to include in the PCSP the paid and unpaid services and supports that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports (unpaid supports provided voluntarily to the individual). This documentation and discussion in the development of the PCSP would build in services that augment/assist the individual and caregiver in the provision of services to achieve the individual’s goals.

Section 1945 of the Social Security Act authorizes Health Home programs for individuals with chronic conditions. States have the option to implement this program, and they have the discretion to determine the chronic conditions to target under the program. Health Homes provide coordination and linkage activities such as comprehensive care management, care coordination, health promotion, comprehensive transitional care (including appropriate follow-up, from inpatient to other settings), patient and family supports, referrals to community and social support services, and the use of health information technology to link services (as feasible and appropriate). This program operates under a “whole-person” philosophy, coordinating all primary, acute, behavioral health, and long-term services and supports to treat the whole person. States receive 90% federal match on Health Home services for the first eight quarters (ten quarters for substance use disorder focused programs only) from the approved effective date of the program.

Section 4802 of the Balanced Budget Act of 1997 authorized the establishment of the Program of All-Inclusive Care for the Elderly (PACE) as a state option. PACE is a program under Medicare, and states can elect to provide PACE services to Medicaid beneficiaries as an optional Medicaid benefit that allows people who otherwise need a nursing home-level of care to



remain in the community. PACE covers all Medicare and Medicaid covered care and services, and other services that the PACE team of health care professionals decides are necessary to improve and maintain a participant's health, and preserve and support the older adult's family unit. Those include services such as adult day care, respite care, meals, home care and personal care.

Beyond these HCBS-related authorities, Medicaid state plan benefits provide states with options to offer an array of services to address the health care needs of beneficiaries that also have the effect of assisting caregivers with their responsibilities. Examples include personal care services, case management services, non-emergency medical transportation, and hospice care. Under the mandatory home health benefit, beneficiaries can receive medical supplies, equipment, and appliances. These state plan services are administered according to state-developed medical necessity criteria to determine who is eligible to receive the service.

Managed long-term services and supports (MLTSS) refers to the delivery of long-term services and supports through capitated Medicaid managed care programs. Increasing numbers of states are using MLTSS as a strategy for expanding home and community-based services, promoting community inclusion, ensuring quality, and increasing efficiency. Medicaid MLTSS programs can be operated under multiple federal Medicaid managed care authorities at the discretion of the state and as approved by CMS, including section 1932(a), 1915(a), section 1915(b), and section 1115. There are requirements and limitations related to each authority, and a managed care authority can be combined with other home and community-based authorities to operate the MLTSS program (for example, a concurrent section 1915(b)/1915(c) waiver).

Note: Additional information can be found on websites for individual state Medicaid agencies (a directory may be accessed at <https://medicaiddirectors.org/about/medicaid-directors/>), websites for state agencies operating programs for individuals with developmental disabilities (a directory may be accessed at <https://www.nasddds.org/state-agencies/>), and websites for state agencies operating programs for older adults and individuals with physical disabilities (a directory may be accessed at <http://www.advancingstates.org/about-nasud/about-state-agencies/list-members>).

PROGRAM NAME: Medicare

TARGET CAREGIVER POPULATION(S): Beneficiaries (and in some cases their Family Caregivers benefit indirectly from these services).

URL(s): <https://Medicare.gov>

AUTHORITY: Medicare: Title XVIII of the Social Security Act.

SUMMARY: The Medicare program offers some limited caregiver supports:

- Advanced care planning services, which can benefit the caregiver and the beneficiary.
- Physician screening of health risks of caregivers, for the benefit of the Medicare beneficiary.
- Care management and chronic care management services.
- Cognitive assessment activities for individuals with signs of dementia, which includes caregiver identification, knowledge, needs, social supports, and willingness to take on caregiving tasks.
- Dialysis training for caregivers of individuals with End Stage Renal Disease.
- Hospice services, including time-limited respite care in a Medicare-certified facility.
- Optional supplemental benefits offered in Medicare Advantage managed care plans, which could include adult day health, personal care, environmental modifications, and transportation, which could indirectly benefit the caregiver.
- Hospital conditions of participation, required in both the Medicare and Medicaid programs, require certain caregivers to be involved in discharge planning.
- An aspect of the Primary Care First Demonstration, the Serious Illness Population option, has aspects of family and caregiver engagement.



- The Nursing Home Resource Center and the consolidated Medicare Compare websites have resources that can help caregivers locate important information.

Food and Drug Administration (FDA)

PROGRAM NAME: Varies

TARGET CAREGIVER POPULATION(S): Patients

URL(s): See below

AUTHORITY: N/A

SUMMARY: The FDA has numerous patient-centered initiatives and programs. While the programs may be of interest to caregivers, these are not aimed at caregivers. More importantly, the FDA programs do not fit into the definitions and purposes of Pub. L. 115-119 – the “Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017” – particularly sections 2 and 3 (b)(1-6). Below is a list of the FDA programs that involve direct patient participation. Some of these programs may impact caregivers in a peripheral fashion – such as providing additional information about the patient’s disease, the use of certain drug products and devices, or may involve caregivers providing information to the FDA. These programs are directed primarily to improving drug and device development by including the patient’s voice in the development process.

FDA

Expanded Access (EA): The FDA Expanded Access program (sometimes called “compassionate use”) is a potential pathway for a patient with a serious or life-threatening disease or condition to use an investigational medical product (drug, biologic, or medical device) for treatment outside of clinical trials when there are no comparable or satisfactory therapies available.

FDA Patient Representative Program®: The FDA Patient Representative Program® is one of the agency’s primary mechanisms for recruiting patients and caregivers who have experience with a disease, condition, or medical device. FDA Patient Representatives are appointed as Special Government Employees (and sometimes Regular Government Employees) to participate in important agency directed assignments.

Center for Biologics Evaluation and Research (CBER)

Patient Engagement Program: The FDA’s Center for Biologics Evaluation and Research’s patient engagement program incorporates patient and caregiver involvement in the Center’s regulatory work through PFDD meetings, patient listening sessions, external conferences, and patient organization meetings.

Center for Devices and Radiological Health (CDRH)

Patient Engagement Advisory Committee (PEAC): The FDA’s Center for Devices and Radiological Health (CDRH) established PEAC meetings to help assure the needs and experiences of patients and caregivers are included as part of the FDA’s deliberations on complex, scientific issues related to medical devices.

Patient and Caregiver Connection (PCC): The Patient and Caregiver-Partner Connection provides CDRH staff with access to aggregated patients’ and caregivers’ perspectives living with their specific disease and using medical devices in the diagnosis, treatment or management of their disease, as well current issues or trends related to medical devices.

Center for Drug Evaluation and Research (CDER)

Patient Focused Drug Development (PFDD): Patient-focused drug development (PFDD) is a systematic approach to help ensure that patients’ experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and evaluation.



Professional Affairs and Stakeholder Engagement (PASE): The CDER Professional Affairs & Stakeholder Engagement (PASE) hosts meetings and listening sessions providing a venue for patients, patient advocacy groups, and their caregivers, to share their experiences living with a disease or condition with FDA staff to help inform drug development.

Office of Patient Affairs (OPA)

Patient Listening Sessions (PLS): The FDA hosts a series of patient listening session meetings that allow patients and caregivers to share their experiences living with a disease or condition and share the most urgent needs with FDA staff to help inform medical product development. This is a collaboration with the National Organization for Rare Disorders (NORD) and the Reagan-Udall Foundation for FDA (RUF).

Patient Engagement Collaborative (PEC): The Patient Engagement Collaborative (PEC) is an ongoing forum of patients, caregivers, and patient advocacy organization representatives that work together to improve transparency, education, and communications between the patient community and the FDA. The group discusses how to achieve more meaningful patient and caregiver engagement in medical product development and other regulatory discussions at the FDA. This initiative is a collaboration with Duke University's Clinical Trials Transformation Initiative (CTTI).

Oncology Center of Excellence (OCE)

Project Community: The OCE's Project Community initiative seeks to improve the quality of bi-directional patient/advocate/community engagement with FDA oncologists and hematologists and people living in communities across the nation "beyond the beltway." Online versions of educational pamphlets and an informational video have also been created for consumer use and are downloadable.

COVID-19 Listening Sessions: The OCE reached out to oncology stakeholders with COVID-19 Guidance Listening Sessions to better understand COVID-related experiences and the pandemic's impact on cancer patients, advocacy groups, and oncology product development. The goal was two-fold: listen directly to cancer patient communities during difficult times and better inform OCE's mission of achieving patient-centered regulatory decision-making through innovation and collaboration.

Conversations of Cancer Program: Trailblazing and dynamic OCE educational, public panel discussion series. Riveting cancer-related social issues in the series are inclusive and diverse.

Project Patient Voice and Oncology Patient-Focused Drug Development: An online platform for patients and caregivers along with their health care providers to look at patient-reported symptom data collected from cancer clinical trials.

Project Facilitate: The OCE's call center to assist oncology care providers in submitting Expanded Access requests.

Health Resources and Services Administration (HRSA)

Federal Office of Rural Health Policy-Community Based Division

PROGRAM NAME: Rural Health Care Services Outreach Program

TARGET CAREGIVER POPULATION(S): Family Caregivers (in rural communities).

URL(s): <https://data.hrsa.gov/tools/rural-health> (search by county or street address to determine rural eligibility).

<https://www.hrsa.gov/rural-health/community/outreach-program-awards>

AUTHORITY: 42 U.S.C. 254c(e). Public Law 116-136.



SUMMARY: The Outreach Program is a community-based grant program aimed towards promoting rural health care services by enhancing health care delivery in rural underserved populations in the local community or region. Through a consortia of local health care and social service providers, communities can develop innovative approaches to challenges related to their specific health needs that expand clinical and services capacity in rural communities.

The overarching goals for the Outreach Program are to 1) Expand the delivery of health care services to include new and enhanced services exclusively in rural communities; 2) Deliver health care services through a strong consortium, in which every consortium member organization is actively involved and engaged in the planning and delivery of services; 3) Utilize community engagement and evidence-based or innovative, evidence informed model(s) in the delivery of health care services; and 4) Improve population health and demonstrate health outcomes and sustainability.

Previously funded Outreach grant programs have brought care to over 2 million rural citizens across the country who often face difficulty gaining access to care. This includes projects focused on the full range of needs in rural communities from workforce, post-acute care services, long-term care services, emergency health care services, public health enhancement, and care coordination.

**Bureau of Health Workforce, Division of Medicine and Dentistry,
Medical Training and Geriatrics Branch**

PROGRAM NAME: Geriatrics Workforce Enhancement Program (GWEP) Tele-Education Program

TARGET CAREGIVER POPULATION(S): Family Caregivers (including patients, families, caregivers, direct care workers, health care providers, and health professions students, residents, fellows, and faculty).

URL(s): <https://www.hrsa.gov/grants/find-funding/hrsa-19-008>

AUTHORITY: PL 116-136, Public Health Service (PHS) Act Title VII, Sections 750 and 753(a), and PHS Act Title VIII, Section 865.

SUMMARY: The purpose of the GWEP Tele-Education Program is to support GWEP activities to advance COVID-19 related telehealth addressing these categories: 1) Prevent – promote the use of telehealth technologies to reduce risk of COVID-19; 2) Prepare – enhance readiness to respond to COVID-19 through telehealth technologies; and 3) Respond – provide access to telehealth technologies to limit spread of COVID-19. This award provides flexibility in using the funding to prevent, prepare for, and respond to COVID-19 as needs evolve. Funding may support a wide range of in-scope activities. For example, funding may be used to support GWEP recipients planning to: 1) Train students and clinicians currently involved in health profession training on providing telehealth-enabled COVID-19 referral for screening and testing, case management, and outpatient care; and/or 2) Maintain primary care functionality away from physical sites, especially for COVID-19 positive, quarantined, elderly and individuals at a higher risk of severe illness. In addition, funds may be used to purchase Wi-Fi access, as well as iPads and other tablets, to be used during telehealth visits between providers and patients, families, and caregivers.

Maternal and Child Health Bureau (MCHB)

PROGRAM NAME: Family-to-Family Health Information Centers (F2F HICs)

TARGET CAREGIVER POPULATION(S): Family Caregivers (including patients, families, caregivers, direct care workers, health care providers, and health professions students, residents, fellows, and faculty).

URL(s): <https://www.hrsa.gov/grants/find-funding/hrsa-18-065>



<https://www.hrsa.gov/library/national-center-family-and-professional-partnerships-ncfpp>

AUTHORITY: Social Security Act, Title V, § 501(c) (42 U.S.C. § 701(c)), as amended by § 216 of the Medicare Access and Children’s Health Insurance Program (CHIP) Reauthorization Act of 2015 (P.L. 114-10), and § 50501 of the Bipartisan Budget Act of 2018 (P.L. 115-123).

SUMMARY: The goal of the F2F HICs Program is to promote optimal health for children and youth with special health care needs (CYSHCN) by helping families and health professionals to partner in health care decision-making and facilitating access to cost-effective, quality health care. The purpose is to provide information, education, technical assistance, and peer support to families of children and youth with special health care needs and the professionals who serve them.

The F2F HICs are statutorily required to:

- Assist families of CYSHCN in making informed choices about health care in order to promote good treatment decisions, cost effectiveness, and improved health outcomes.
- Provide information regarding the health care needs of, and resources available to CYSHCN.
- Identify successful health care delivery models for CYSHCN.
- Develop, with representatives of health care providers, managed care organizations, health care purchasers, and appropriate state agencies, a model for collaboration between families of CYSHCN and health professionals.
- Provide training and guidance regarding the care of CYSHCN.
- Conduct outreach activities to families of CYSHCN, health professionals, schools, and other appropriate entities and individuals.
- Staff centers with families of CYSHCN who have expertise in federal and state public and private health care systems, and with health professionals.

Indian Health Service (IHS)

PROGRAM NAME: *Varies*

TARGET CAREGIVER POPULATION(S): Family Caregivers; Kinship Families and Grandfamilies (i.e., American Indians and Alaska Natives defined in statute as eligible for services from IHS, a tribe or tribal Organization operating under the ISDEAA, or an Urban Indian Organization funded by IHS under the IHCA).

URL(s): <https://www.ihs.gov/>

AUTHORITY: The United States Constitution, Article I, Section 8 specifically addresses the federal government’s primary role in dealing with Indians. Consistent with that authority, Congress enacted several statutes authorizing the federal government to provide health care services to American Indians and Alaska Natives. The Snyder Act of 1921 (25 U.S.C 13) and the Indian Health Care Improvement Act (IHCA) [25 U.S.C. 1601-1685] provide specific legislative authority for Congress to appropriate funds specifically for the health care of Indian people.

In addition, numerous other laws, court cases, and executive orders reaffirm the unique relationship between tribal governments and the federal government.

The Indian Self-Determination and Education Assistance Act (ISDEAA) (P.L. 93-638, as amended), provide tribes the option of exercising their right to self-determination by assuming control and management of programs previously administered by the federal government.

SUMMARY: No distinct program or budget line for Caregiver Support. IHS clinical services provide caregiver support as a function of clinical care for elders. IHS Public Health Nursing (PHN) integrates caregiver support into usual outreach and support for frail elders and individuals with Alzheimer’s disease and related dementias.

The IHS partnered with the Administration on Aging/Administration for Community Living (AoA/ACL), the VA REACH Training Center, and the University of Tennessee Health Sciences



Center in an effort funded by the non-profit Rx Foundation to adapt and spread the Resources to Enhance Alzheimer's Caregiver Health (REACH) U.S. Department of Veterans Affairs (VA) model of caregiver support. According to data provided by the REACH Training Center in February 2018, over the three funded years of REACH into Indian Country, 80 caregiver coaches were trained and certified in 56 distinct tribal communities. Coaches were Public Health Nurses and caregiver support staff funded through Title VI of the Older Americans Act (ACL/AoA). These caregiver coaches reported delivery of REACH services to 55 caregivers. Caregiver support activity was unevenly distributed among the 50+ communities in which caregivers have been certified; in many of these communities no caregivers have been enrolled. The funding for that program has ended.

In follow-up to the REACH into Indian Country initiative, the IHS PHN program is working in partnership with the VA Geriatric Scholars Program on further supporting caregivers through the ABCD (Addressing Challenging Behaviors with Dementia) training for IHS and tribal programs. This effort is on hiatus as a result of the COVID-19 pandemic.

National Institutes of Health (NIH)

PROGRAM NAME: National Institutes of Health, various programs

TARGET CAREGIVER POPULATION(S): Family Caregivers; Kinship Families and Grandfamilies.

URL(s): [National Alzheimer's Project Act](#)

AUTHORITY: NIH is organized into 27 Institutes and Centers, and the Office of the Director, which each have their own mission and functions, separate appropriations, and statutory authorities. The majority of caregiving research funded at NIH falls within a combined Alzheimer's disease and Alzheimer's disease and related dementias (AD/ADRD) research, condition, and disease category, which was established by the NIH to facilitate its implementation of the [National Alzheimer's Project Act](#) (NAPA). Although caregiving research related to AD/ADRD is not separately reported, the NIH does publicly report its investments across all caregiving research.

SUMMARY: NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. NIH carries out its mission through the conduct and support of intramural (primarily at NIH) and extramural (researchers and organizations outside of NIH) biomedical and behavioral research, research training, research infrastructure, and communications. As a grant-making Operating Division of HHS, NIH makes extramural awards through its Institutes and Centers in the form of grants, cooperative agreements, and contracts awarded to institutions of higher education, governmental organizations, non-profit research organizations, for-profit organizations, and individuals.

The National Institute on Aging (NIA): NIA's [Health Information](#) webpages cover a broad range of health topics and include numerous tips and resources on caregiver health and for [family caregivers](#). The NIA [Caregiving](#) webpage presents tips for caregivers and caring for older adults, as well as information on long-distance caregiving, advance care planning, and planning for long-term care. The [Alzheimer's Caregiving](#) webpage addresses a broad range of topics specific to AD/ADRD care partners and families. NIA also provides [Clinical Trials Information for the Public](#), which includes clinical trials focused on caregiving.

The National Institute of Nursing Research (NINR): NINR's website includes videos, tear-off pads, resource cards, fact sheets, a provider toolkit, and brochures for families with seriously ill children and health care providers as part of their [Palliative Care: Conversations Matter®](#) campaign, aimed at increasing the use of palliative care for children and teens living with serious illnesses.



The National Cancer Institute's (NCI): NCI's [Resources for Caregivers](#) webpage includes information about caring for the "cancer patient" and coping tips for caregivers, which can be found at: [Support for Caregivers of Cancer Patients](#).

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD): NICHD's Health Information webpages offer brochures, booklets, reports, and other materials on topics within its research portfolio for different audiences, and the [Grandparent Videos](#) section features [Safe Infant Sleep for Grandparents and Other Trusted Caregivers](#).

National Library of Medicine (NLM): [MedlinePlus](#) is a free online health information resource for patients and their families and friends. It is a service that NLM provides in its mission to present high-quality, relevant health and wellness information that is trusted, easy to understand, and free of advertising, in both English and Spanish. Included among the hundreds of Health Topics covered in MedlinePlus are three separate pages devoted to caregivers, which provide a comprehensive list of caregiver consumer health materials, consisting of basic information about how caregiving affects health as well as links to tips for stress management and treatments and therapies, journal articles, and caregiver clinical trials, as well as patient handouts for caregivers of children and adults: [Caregivers](#); [Caregiver Health](#); and [Caregivers for Alzheimer's Disease](#). In addition, while the [NLM Resources for Caregivers](#) webpage was sunset on September 30, 2020, the information and links presented remain current.

NIH Funding Opportunity Announcements for Research on Caregiving: [NIH Guide for Grants and Contracts](#); NIH's official publication of current notices of funding opportunity announcements (FOAs) calling for research applications focused on caregiving.

NIH Clinical Trials on Caregiving: [The NIH Clinical Trials and You](#) website is a resource for people who want to learn more about clinical trials.

Substance Abuse and Mental Health Services Administration (SAMHSA)

PROGRAM NAME: The Family Support Technical Assistance Center

TARGET CAREGIVER POPULATION(S): Family Caregivers; Kinship Families and Grandfamilies. (The Family Support Technical Assistance Center (FAM-CoE) provides information to persons and communities across the country who are caring for family members with serious mental illness (SMI).

Statewide Family Network (SFN) program grants provide support to families who are raising children with serious emotional disturbance (SED). "Family" is defined by the family, and includes grandparents.

URL(s): <https://www.samhsa.gov/grants/grant-announcements/fg-20-002>

AUTHORITY: Funded by SAMHSA.

SUMMARY: SAMHSA recognizes the critical role families play in addressing mental health and substance use disorders and the toll such disorders take on families across the country. Each one of the SFN grantees is required to have the availability of relevant information to the public such as toll-free phone lines, newsletters, and the like. Virtually all grantees now offer an electronic newsletter.

The Fam-CoE will focus on training and education of the general public and health care practitioners on the importance of family supports and services and the integration of these services into mental and substance use disorder treatment programs. The Fam-CoE will also provide much needed resources and education directly for families.

Statewide Family Network program grants. The purpose of this program is to enhance state capacity and infrastructure to better respond to the needs of children and adolescents with serious emotional disturbances and their families by providing information, referrals, and



support to families who have a child with a mental health challenge, and to create a mechanism for families to participate in state and local mental health services planning and policy development. This grant program is the CMHS primary initiative that responds to the needs of grandparents as caregivers to children and youth with SED.

The Statewide Family Network program builds on the work of SAMHSA's Center for Mental Health Services, which helped to establish a child and family focus in programs serving children and adolescents with mental health challenges around the country. Today, nearly every state has active family organizations dedicated to promoting systems of care that are responsive to the needs of children and adolescents with mental health challenges and their families. Although significant progress has been made, further support will ensure self-sufficient, empowered networks that will effectively participate in state and local mental health services planning and health care reform activities related to improving community-based services for children and adolescents with mental health challenges and their families.

Child, Adolescent, and Family Branch

PROGRAM NAME: Statewide Family Network Program Grants

TARGET CAREGIVER POPULATION(S): Family Caregivers (Persons and communities across the country caring for family members with severe mental illness).

URL(s): <https://www.samhsa.gov/grants/grant-announcements/sm-15-001> Programs have toll free lines and newsletters.

AUTHORITY: Funded by SAMHSA.

SUMMARY: The purpose of this program is to enhance state capacity and infrastructure to better respond to the needs of children and adolescents with serious emotional disturbances (and their families) by providing information, referrals, and support to families who have a child with a mental health challenge, and to create a mechanism for families to participate in state and local mental health services planning and policy development. This grant program is the primary initiative that responds to the needs of grandparents and caregivers to children and youth with SED. Statewide Family Network Program builds on the work of SAMHSA's Center for Mental Health Services, which helped to establish a child and family focus in programs serving children and adolescents with mental health challenges. Today, nearly every state has active family organizations dedicated to promoting systems of care that are responsive to the needs of children and adolescents with mental health challenges and their families. Although significant progress has been made, further support will ensure self-sufficient, empowered networks that will effectively participate in state and local mental health services planning and health care reform activities related to improving community-based services for children and adolescents (and their families).

The Statewide Family Network grants provide for infrastructure development as well as information and communication.

HHS Office of the Secretary (OS)

PROGRAM NAME: Office of the Assistant Secretary for Planning and Evaluation (ASPE)

TARGET CAREGIVER POPULATION(S): Family Caregivers; Kinship Families and Grandfamilies (ASPE's Primary audience is the Secretary and other policy makers making decisions about the health and well-being of the American population).

URL(s): <http://aspe.hhs.gov>

AUTHORITY: N/A.



SUMMARY: The Office of the Assistant Secretary for Planning and Evaluation (ASPE) advises the Secretary of the Department of Health and Human Services on policy development in health, disability, human services, data, and science, and provides advice and analysis on economic policy. ASPE leads special initiatives; coordinates the Department's evaluation, research, and demonstration activities; and manages cross-Department planning activities such as strategic planning, legislative planning, and review of regulations. Integral to this role, ASPE conducts research and evaluation studies; develops policy analyses; and estimates the cost and benefits of policy alternatives under consideration by the Department or Congress.

Within ASPE, the Office of Behavioral Health, Disability, and Aging Policy (BHDAP) focuses on policies and programs that support the independence, productivity, health, and well-being of people with disabilities, people with mental and substance use disorders (behavioral health), and older adults.

BHDAP's portfolio includes, but is not limited to, behavioral health treatment and coverage issues; issues related to the need for and use of long-term services and supports; Alzheimer's disease and related dementias; and issues related to behavioral health and long-term care quality and financing through Medicare, Medicaid, and private insurance. BHDAP works closely with the ACL, SAMHSA, the CMS, and the NIH, among other HHS and federal agencies focused on aging, disability, and behavioral health.

The Division of Long-Term Care Policy focuses on the long-term care and personal assistance needs of people of all ages with chronic disabilities. Areas of focus include informal caregiving; assessing the interaction between health care, chronic care, long-term care, and supportive services needs of persons with disabilities across the age spectrum; determining service use and program participation patterns; and coordinating the development of long-term care data and policies that affect the characteristics, circumstances, and needs of people with long-term care needs, including older adults and people with disabilities.

The Division of Disability and Aging Policy is responsible for policy development, coordination, research and evaluation of policies and programs focusing on persons with disabilities and older Americans. This includes measuring and evaluating the impact of all programs authorized by the Older Americans Act. Aging activities related to older Americans are carried out in coordination with other HHS agencies and organizations. The Division is also responsible for supporting the development and analysis of crosscutting disability and aging data and policies within HHS and in other federal agencies.

The Division of Behavioral Health and Intellectual Disabilities Policy focuses on financing, delivery, and quality of services and supports for individuals with mental illnesses, substance use disorders, or intellectual disabilities. Areas of focus include coverage and payment issues in private insurance, programs and policies of Medicare and Medicaid, quality and consumer protection issues, and programs and policies of HHS agencies as they affect adults, children, and youth with mental health conditions, substance abuse, or intellectual disabilities.

Family caregiving has been a focus of many BHDAP research and reports. Some examples include:

Economic Impacts of Programs to Support Caregivers

<https://aspe.hhs.gov/basic-report/economic-impacts-programs-support-caregivers-final-report>

Assessing the Out-of-Pocket Affordability of Long-Term Services and Supports

<https://aspe.hhs.gov/basic-report/assessing-out-pocket-affordability-long-term-services-and-supports-research-brief>

How Many Older Adults Can Afford To Purchase Home Care? <https://aspe.hhs.gov/basic-report/how-many-older-adults-can-afford-purchase-home-care>

What Is the Lifetime Risk of Needing and Receiving Long-Term Services and Supports? <https://aspe.hhs.gov/basic-report/what-lifetime-risk-needing-and-receiving-long-term-services-and-supports>



Community-Dwelling Older Adults with Dementia and Their Caregivers: Key Indicators from the National Health and Aging Trends Study

<https://aspe.hhs.gov/basic-report/community-dwelling-older-adults-dementia-and-their-caregivers-key-indicators-national-health-and-aging-trends-study>

PROGRAM NAME: Office of the National Coordinator (ONC) For Health Information Technology

TARGET CAREGIVER POPULATION(S): Family Caregivers; Kinship Families and Grandfamilies.

URL(s): <https://www.healthit.gov/>

AUTHORITY: The position of National Coordinator was created in 2004, through an executive order, and legislatively mandated in the Health Information Technology for Economic and Clinical Health Act ([HITECH Act](#)) of 2009.

SUMMARY: One of the big challenges for caregivers is the ability to coordinate care for their care recipient. This is particularly difficult when utilizing health care and human/social/community services from a variety of providers, most of whom are not connected to one another. Furthermore, it is very difficult to collect and track all the information and medical records, and consolidate them in one place, not to mention the challenge of permissions needed to access records by a caregiver.

While many patients can access their medical information through multiple provider portals, the current ecosystem is frustrating and cumbersome. The more providers they have, the more portals they need to visit, the more usernames and passwords they need to remember. In the end, these steps make it hard for patients and their caregivers to aggregate their information across care settings and prevent them from being empowered consumers.

Interoperable health information exchange can improve care coordination including; a historical and current view of the patients health record and the care they have received; Access to longitudinal health information that enables improved efficiencies, improved quality of care, and improved health outcomes; patient and caregiver communications with providers; transitions between health care settings [inpatient, ambulatory, acute care, long-term and post-acute care (LTPAC), and home and community-based services].

Data should be usable across the continuum of care and beyond the traditional health care system, including community-based services. As we move forward, we expect to include more information about a person's health (SDOH, Community-based care, etc.) within the core information that is shared.

In 2016, the 21st Century Cures Act was passed with near unanimous bipartisan support and signed into law with two major provisions including: patient access to, and the ability to control their health information; and interoperability of health information. This will require all health care providers to share a patient's health data with one another to better enable care coordination, view health history, lab results, medication information, etc.

In ONC's role in coordinating health information technology (health IT) innovators are working to develop strategies to support the use of mobile apps to help individuals manage their own health or the health and care of a loved one. A robust health app ecosystem can also lead to disease-specific apps and allow patients to share their health information with researchers working on clinical trials to test a drug or treatment's efficacy or monitoring outcomes like those in the NIH's All of Us Research Program.

Final Rule released in March 2020:

<https://www.hhs.gov/about/news/2020/03/09/hhs-finalizes-historic-rules-to-provide-patients-more-control-of-their-health-data.html#:~:text=The%20ONC%20Final%20Rule%20identifies,certified%20health%20IT%2C%20health%20information>



HHS finalized two transformative rules that will give patients unprecedented safe, secure access to their health data. Multiple administrations and numerous laws have pursued interoperability, and today, these rules finally deliver on giving patients true access to their healthcare data to make informed healthcare decisions and better manage their care. Putting patients in charge of their health records is a key piece of giving patients more control in healthcare, and patient control is at the center of the Trump administration's work toward a value-based healthcare system.

ONC's final rule establishes secure, standards-based application programming interface (API) requirements to support a patient's access and control of their electronic health information. APIs are the foundation of smartphone applications (apps). As a result of this rule, patients will be able to securely and easily obtain and use their electronic health information from their provider's medical record for free, using the smartphone app of their choice.



U.S. Department of Education

PROGRAM NAME: Rehabilitative Services Administration Programs

TARGET CAREGIVER POPULATION(S): Kinship Families and Grandfamilies (including Parents, Guardians, State Vocational Rehabilitation)

URL(s): <https://www.raisecenter.org/>

AUTHORITY: Rehabilitation Act of 1973, as amended (29 U.S.C. §773(c)(2)) establishes a parent information and training program (RSA PTIs), administered by the Rehabilitation Service Administration (RSA) under the Office of Special Education and Rehabilitative Services (OSERS).

SUMMARY: The purpose of the program is to provide information, training, and resources on Youth Transition, the period between adolescence and adulthood, and the transition between IDEA services and postsecondary, rehabilitative, and adult services. There are currently eight RSA PTIs throughout the US that provide various training and programming to youth and young adults with disabilities and their families, professionals, and parent training and information centers funded under IDEA. The current RSA PTIs support various entities within their region, to include national coverage. In addition, the National Resources for Advocacy, Independence, Self-determination, and Employment (RAISE) Technical Assistance Center, also funded under the program, provides technical assistance and support to the eight RSA PTIs and has a website with useful resources for families and others.

PROGRAM NAME: Elementary and Secondary Education Act (ESEA) Programs

TARGET CAREGIVER POPULATION(S): Kinship Families and Grandfamilies (including parents, guardians, and schools).

URL(s): <https://oese.ed.gov/families/>

AUTHORITY: The SFEC program is authorized under title IV, part E of the Elementary and Secondary Education Act of 1965, as amended (ESEA).

SUMMARY: The purpose of the Statewide Family Engagement Centers (SFEC) program is to provide financial support to organizations that provide technical assistance and training to State Educational Agencies (SEAs) and Local Educational Agencies (LEAs) in the implementation and enhancement of systemic and effective family engagement policies, programs, and activities that lead to improvements in student development and academic achievement. The eligible entities for this grant are statewide organizations (or consortia of such organizations) in partnership with an SEA to establish SFECs that (1) carry out parent education and family engagement in education programs, and (2) provide comprehensive training and technical assistance to SEAs, LEAs, schools identified by SEAs and LEAs, organizations that support family-school partnerships, and other such programs.

The SFEC program seeks to promote high-impact cradle-to-career family, school, and community engagement by funding centers that build the capacity of all stakeholders—including families, SEAs, LEAs, school-level staff and personnel, and community based organizations—to engage in effective partnerships that support student achievement and school improvement and increase the number of high-quality educational options available to families.

A few grantees are conducting work directly targeting grandparents. The West Virginia Center co-hosted professional development for grandparents and great-grandparents raising grandchildren. The Ohio Center has recently begun a project to strengthen the support and engagement of grandparents raising school-age kids. They are completing a review of the research in this area and will be releasing a brief on the results. They will also begin developing a training to pilot with schools and a program for grandparents.



PROGRAM NAME: Office of English Language Acquisition (OELA)

TARGET CAREGIVER POPULATION(S): Kinship Families and Grandfamilies. OELA provides guidance to families to help them choose educational services and supports that best fit their child's needs.

URL(S): <https://www2.ed.gov/about/offices/list/oela/index.html>

AUTHORITY: OELA's appropriations, programs and services are authorized under Title III of the Elementary and Secondary Education Act (ESEA) and reauthorized under Title III of the Every Student Succeeds Act (ESSA).

SUMMARY: The U.S. Department of Education's Office of English Language Acquisition (OELA) provides national leadership to help ensure that English Learners (ELs) and immigrant students attain English proficiency and achieve academic success. In addition to preserving heritage languages and cultures, OELA is committed to prompting opportunities for biliteracy or multiliteracy skills for all students.

OELA also funds research and evaluation studies regarding ELs as well as the National Clearinghouse for English Language Acquisition (NCELA). NCELA's mission is to collect, coordinate, and convey a broad range of research and resources in support of an inclusive approach to high quality education for ELs. To fulfill its mission, NCELA supports OELA in a variety of activities in addition to serving other stakeholders involved in EL education including State Educational Agencies (SEAs), teachers and other practitioners, parents, university faculty, administrators, and federal policymakers.

Office of Special Education and Rehabilitative Services (OSERS), Office of Special Education Programs (OSEP)

PROGRAM NAME: Individuals with Disabilities Education Act (IDEA) Programs

TARGET CAREGIVER POPULATION(S): Kinship Families and Grandfamilies.

URL(s): <https://sites.ed.gov/idea/parents-families/>

AUTHORITY: P.L. 101-476 (IDEA includes "an individual acting in the place of a natural or adoptive parent (including a grandparent, stepparent, or other relative) with whom the child lives, or an individual who is legally responsible for the child's welfare" (20 U.S.C. § 1401) in its definition of parent).

SUMMARY: Part C of IDEA: Congress established the Program for Infants and Toddlers with Disabilities in IDEA in 1986. Part C of the current IDEA legislation (20 U.S.C. §§ 1431-1444) authorizes a grant program to states to maintain and implement a statewide, comprehensive, coordinated, multidisciplinary interagency system to provide early intervention services for infants and toddlers with disabilities and their families. In order for a state to participate in the program, it must assure that early intervention services will be available to all infants and toddlers with disabilities and their families.

Part C early intervention services are designed to ensure that infants or toddlers with disabilities are identified and evaluated. An infant or toddler with a disability means an individual under three years of age who needs early intervention services because they are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more areas, or has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. The areas under consideration are cognitive, physical, communication, social or emotional, and adaptive development. States have discretion in terms of defining developmental delay and diagnosed conditions; therefore, the percent of infants and toddlers served under Part C varies from state to state. At the discretion of the state, at-risk infants or toddlers may also be served under Part C. Services are detailed for each child and their family in an Individualized Family Service Plan (IFSP), and parents are an integral member



of the team developing the IFSP. To the maximum extent feasible, services are to be provided in “natural environments,” including the home or with other infants and toddlers without disabilities.

Part B of IDEA: Part B of IDEA (20 U.S.C. §§ 1411-1419) ensures that all children with disabilities ages 3 through 21 have available to them a Free and Appropriate Education (FAPE) that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.

Special education is the provision of specially designed instruction that meets the unique needs of a child with a disability. IDEA Part B lists 13 different disability categories under which a child may be found eligible for special education and related services. These categories are autism, deafness, deaf-blindness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment including blindness. States may also adopt developmental delay as a disability category for children ages three through nine or for a subset of that age range.

Special education and related services must be provided, to the maximum extent appropriate, in the least restrictive environment (LRE) based on the child’s unique needs. The LRE Requirements indicate a strong preference for educating children with disabilities in general education settings with appropriate aids and supports alongside their peers without disabilities to the maximum extent appropriate. Each child’s Individualized Education Program (IEP) states the services and accommodations the child will receive. Parents are important members of the team that develops the IEP. States are also required to have a system to ensure that all children with disabilities residing in the state, regardless of the severity of their disability, and who are in need of special education and related services, are identified, located, and evaluated.

Part D of IDEA: Part D of IDEA (20 U.S.C. §§ 1450-1482) funds national activities that support the provision of early intervention and special education services to infants, toddlers, children, and youth with disabilities. These activities include state personnel development grants to support current personnel; grants to institutions of higher education to prepare early intervention and special education personnel, including related services; grants to fund technical assistance and dissemination centers, and model demonstration centers, that promote best practices in supporting children with disabilities; and grants for technology projects that disseminate accessible materials and media and promote children with disabilities’ effective use of technology.

Part D also funds the parent training and information center program (20 U.S.C. §§ 1470-1473), which provides direct services to families of children with disabilities, including children who may not yet be identified as having a disability or may be inappropriately identified. The purpose of the program is to ensure that children with disabilities and their parents receive training and information on their rights, responsibilities, and protections under IDEA; that the training and information is designed to assist the children in meeting developmental and functional goals and challenging academic achievement goals that prepare them to lead as productive and independent adult lives as possible; and that parents and youth develop the skills necessary to cooperatively and effectively participate in planning and decision making relating to early intervention, educational, and transitional services.

The program consists of 99 grants of three types: Parent Training and Information Centers (PTIs) in every state and territory; Community Parent Resource Centers (CPRCs) in underserved communities; Regional Parent Technical Assistance Centers (PTACs) and a national technical assistance center, the Center for Parent Information and Resources (CPIR).

PTIs and CPRCs provide direct services to all families of children with disabilities and youth with disabilities, including families of children who are suspected of having a disability, in the form of in-person, telephone, and electronic consultations, in-person and web-based trainings, support groups, and leadership development activities.



While PTIs and CPRCs primarily focus on educational issues, they also connect families with relevant local and state resources applicable to kinship families. The national Center for Parent Information and Resources' website contains a list of all the PTIs and CPRCs throughout the country and a curated list of informational resources for families and professionals.



U.S. Department of Labor

Wage and Hour Division

PROGRAM NAME: The Family and Medical Leave Act of 1993 (FMLA)

TARGET CAREGIVER POPULATION(S): Family Caregivers; Kinship Families and Grandfamilies (e.g., employees of private sector employers with 50 or more employees and public agencies regardless of the number of employees they employ).

URL(s): www.dol.gov/agencies/whd/fmla

AUTHORITY: (29 U.S.C. 2601), signed into law on February 5, 1993, and effective August 5, 1993.

SUMMARY: The FMLA is a federal law that provides eligible employees of covered employers with unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance under the same terms and conditions as if the employee had not taken leave. The U.S. Department of Labor's Wage and Hour Division (WHD) is responsible for administering and enforcing the FMLA for most employees. Additionally, WHD offers a wide variety of materials to help the public understand the law. WHD's FMLA website, www.dol.gov/agencies/whd/fmla, is consistently one of the Department's most frequently visited web pages. In 1995, 2000, 2012, and 2018, the Department surveyed employees and employers to gain knowledge about how individuals understand and experience FMLA (<https://www.dol.gov/agencies/oasp/evaluation/fmla2018>).

WHD does not enforce the FMLA for most federal employees. Most employees of the U.S. government, if they are covered by the FMLA, are covered under Title II of the FMLA, which is administered by the U.S. Office of Personnel Management (OPM).

The FMLA generally applies to private sector employers with 50 or more employees. Public agencies are covered employers under the FMLA, regardless of the number of employees they employ. Local educational agencies are also covered regardless of the number of employees they employ. Such educational agencies include public school boards, public elementary and secondary schools, and private elementary and secondary schools. An eligible employee is one who works for a covered employer, has worked for the employer for at least 12 months as of the date the FMLA leave is to start, has at least 1,250 hours of service for the employer during the 12-month period immediately before the date the FMLA leave is to start (a different hours of service requirement applies to airline flight crew employees), and works at a location where the employer employs at least 50 employees within 75 miles of that worksite as of the date when the employee gives notice of the need for leave. Among other qualifying reasons for leave, eligible employees may take up to 12 workweeks of leave in a 12-month period to care for a spouse, son, daughter, or parent who has a serious health condition, including incapacity due to pregnancy and for prenatal medical care; and up to 26 workweeks of leave during a single 12-month period to care for a covered service member with a serious injury or illness when the employee is the spouse, son, daughter, parent, or next of kin of the service member.

WHD has issued Administrator Interpretations ([FMLA 2013-1 and 2010-3](#)) and plain language fact sheets regarding the availability of leave to employees who have or have had an "in loco parentis" relationship to a child or parent, and providing guidance on the FMLA definition of a son or daughter who is 18 or older and incapable of self-care because of a disability. WHD has also provided examples and guidance on grandparent and sibling relationships that may qualify, in certain circumstances, as covered "in loco parentis" caregiving relationships.

Every employer covered by the FMLA must provide a general notice to their employees regarding the FMLA. To satisfy the general notice requirement, employers must display or post a general notice (a poster). If a significant portion of an employer's employees do not read and write English, the employer must provide the general notice in a language in which they can read and write. When providing FMLA notices to sensory-impaired individuals, employers must also comply with all applicable requirements under federal and state law. Employers may make



the poster available electronically, create their own poster, or use another format. In addition to displaying a poster, if a covered employer has any FMLA eligible employees, it must also provide each employee with a general notice about the FMLA in the employer's employee handbook or other written materials about leave and benefits. If no handbook or written leave materials exist, the employee must distribute this general notice to each new employee upon hire. When an employee requests FMLA leave, or when the employer acquires knowledge that an employee's leave may be for a FMLA-qualifying reason, the employer must notify the employee of his or her eligibility to take FMLA leave and provide a rights and responsibilities notice. WHD makes available posters and optional-use forms for notifying employees of their FMLA eligibility, rights, and responsibilities, and leave designation on its website at <https://www.dol.gov/agencies/whd/fmla/forms>.

Division of Strategic Investments, Office of Workforce Investment

PROGRAM NAME: Strengthening Working Families Initiative (SWFI) grant program

TARGET CAREGIVER POPULATION(S): Family caregivers

URL(s): <https://www.dol.gov/agencies/eta/skills-grants/h1-b-skills-training>

AUTHORITY: Section 414(c) of the American Competitiveness and Workforce Improvement Act of 1998 (ACWIA), as amended (codified at 29 USC 3224a).

SUMMARY: SWFI grants assist low- to middle-skilled parents in accessing the affordable, quality child care they need to earn an education, participate in training programs, and ultimately compete for better-paying jobs in emerging industries. These projects are also connecting workforce and child care systems to address the needs of working parents beyond the grant period. DOL awarded approximately \$54 million in SWFI grants to 14 partnerships providing services to 13 states in June 2016. The grant period of performance was four years, and some grantees received up to one-year extensions. All grantees will complete their period of performance by June 30, 2021. No further rounds are anticipated.

The SWFI grant program is one of several H-1B Skills Training Grants fund projects that provide training and related activities to workers to assist them in gaining the skills and competencies needed to obtain or upgrade employment in high-growth industries or economic sectors. These grants are supported by user fees paid by employers seeking high skilled foreign workers under the H-1B visa program. The goal of the training grants is to prepare Americans for high skill jobs, reducing the dependence on foreign labor. Funds are authorized by Section 414(c) of the American Competitiveness and Improvement Act of 1998 (ACWIA), as amended (29 USC 3224a).

Employment and Training Administration, Office of Workforce Investment, Division of Youth Services

PROGRAM NAME: Workforce Innovation and Opportunity Act (WIOA) Youth Formula Funded

TARGET CAREGIVER POPULATION(S): Family Caregivers; Kinship Families and Grandfamilies (e.g., youth facing barriers to education, training, and employment)

URL(s): <https://www.dol.gov/agencies/eta/youth/wioa-formula>

AUTHORITY: 29 U.S.C. 3101, Title I, Chapter 2, July 2015

SUMMARY: Out-of-school youth (i.e., not attending school), ages 16-24 and with one or more barriers to employment including school dropout, high school graduate and basic skills deficient or English language learner, offender, homeless or runaway, foster care, pregnant or parenting, disability, and low income who requires additional assistance for education or employment.



In-school youth who is attending school, ages 14-21, low income and has one or more barriers to employment including basic skills deficient, English language learner, offender, homeless or runaway, foster care, pregnant or parenting, disability, and requires additional assistance.

WIOA Youth Formula Funded activities include 14 program elements: tutoring; alternative secondary school services; paid and unpaid work experiences, which include summer and year round employment opportunities, pre-apprenticeship programs, internships and job shadowing, and on-the-job training; occupational skill training; education offered concurrently with workforce preparation and training; leadership development opportunities; supportive services; mentoring; follow-up services; comprehensive guidance and counseling; financial literacy education; entrepreneurial skills training; services that provide labor market and employment information; and postsecondary education and training preparation activities.

A minimum of 75% of the Youth funds allocated to states and local areas must be used to provide services to out-of-school youth.



U.S. Department of Veterans Affairs

Office of Community Engagement (OCE)

PROGRAM NAME: *Varies*

TARGET CAREGIVER POPULATION(S): Family Caregivers (i.e., Veterans, their families, caregivers, and survivors).

AUTHORITY: 38 U.S.C. § 8301; 38 U.S.C. § 523; The Economy Act, 31 U.S.C. 1535; 38 U.S.C. 1710B and 1720B; The Economy Act, 31 U.S.C. 1535; The Domestic Volunteer Service Act of 1973, as amended (DVSA) (42 U.S.C. 5028), The National and Community Service Act of 1990, as amended (NCSA), 42 U.S.C. 12511(34), 12651b(g)(10)(B) and 12657.

SUMMARY: OCE serves as a trusted resource and a catalyst for the growth of effective partnerships at the national, state, and community level and as a facilitator/access point for public and private entities interested in partnering with VA's Veterans Health Administration (VHA) to benefit Veterans, their families, caregivers, and survivors. Nine partnerships that directly impact caregivers include:

CancerCare (in development): The goal of this partnership is to improve care and outcomes of Veterans, their families, caregivers, and survivors diagnosed with any type of cancer.

<https://www.cancercares.org/>

Cancer Support Community: The purpose of this partnership is to provide cancer related resources and support services to Veterans, VHA health care professionals, and Veterans' family members and caregivers; provide specific resources that focus on reducing social isolation and hopelessness to Veterans with cancer; and increase Veterans' awareness of an opportunity to participate in the voluntary CSC Cancer Experience Registry (CER) to document the Veteran cancer patient experience. <https://www.cancersupportcommunity.org/>

American Lung Association: The goal of this partnership is to enhance services to Veterans, their families, and caregivers through collaborative education and services for Veterans living with lung disease. <https://www.lung.org>

VHA/AmeriCorps Choose Home Partnership: The purpose of this partnership is to provide homemaker services and in-home respite care services to eligible Veterans so that those Veterans can continue to remain in their own homes and live more independently. <https://www.va.gov/opa/pressrel/pressrelease.cfm?id=5277> or <https://www.americorps.gov/about/what-we-do/veterans>

Imerman Angels (in development): The partnership with Imerman Angels will provide increased outreach to Veterans and their families and caregivers in and out of the VA system, with the specific aim of improving access to a cancer patient support network, educational material, and cancer survivor mentor training for Veterans and caregivers. <https://imermanangels.org/>

American Kidney Fund (AKF): The partnership will provide support for Veterans, family members, caregivers, and survivors diagnosed with kidney disease by helping them to live healthier lives through awareness, education, and sharing resources about prescreening and receiving appropriate treatment. <https://www.kidney.org/>

Arthritis Foundation (AF) (in development): The partnership will provide education and support for Veterans, family members, caregivers, and survivors diagnosed with arthritis. <https://www.arthritis.org/>

American Cancer Society (ACS) (in renewal development): This partnership provides the advancement and improvement of quality of life for Veterans, family members, and caregivers who are at-risk, living with, or surviving cancer. <https://www.cancer.org/>



American Diabetes Association (ADA) (in development): This partnership will provide awareness and education for Veterans, family members, caregivers, and survivors who are at-risk or diagnosed with diabetes. <https://www.diabetes.org/>

Office of Research & Development

PROGRAM NAME: Elizabeth Dole Center of Excellence for Veteran and Caregiver Research

TARGET CAREGIVER POPULATION(S): Family Caregivers (i.e., Veterans, Caregivers of Veterans as well as Children and Youth living in caregiving households).

URL(s): <https://www.hsrd.research.va.gov/centers/dole/default.cfm/>

AUTHORITY: 38 U.S. Code § 7303.

SUMMARY: The Elizabeth Dole Center of Excellence for Veteran and Caregiver Research was created as part of the VA Choose Home Initiative. The goal of Choose Home is to allow Veterans to remain in their homes rather than institutional care. The purpose of the Center is to expand VA capacity to deliver integrated, Veteran and caregiver-partnered, data-driven approaches to care. The center is conducting complimentary projects whose results will inform VA operational leaders in expanding VA caregiver programs. The Center is multi-site, with locations in San Antonio, Palo Alto, Salt Lake City, Miami, and Canandaigua. These programs have 4 key components: (1) pilot projects related to caregiver support; (2) interviews of Veterans, caregivers, and other stakeholders to assess measures that are most meaningful to caregivers; (3) data analytics to assess the types of home-based care services that are most effective for different Veteran populations, and (4) an assessment of the lived experiences of youth in caregiving households.

Veterans Health Administration (VHA)

PROGRAM NAME: VA Voluntary Services (VA Volunteer In-Home Visitor Program and Compassionate Contact Corps Program)

TARGET CAREGIVER POPULATION(S): Family Caregivers (i.e., Any Veteran referred by their clinician is eligible for these programs).

URL(s): Volunteers and community partners can learn more about these programs by contacting their local VA medical center. To locate the nearest facility, visit: www.volunteer.va.gov. Toolkits and the Program Implementation Guide will be accessible to Voluntary Service Officers at local facilities executing the program.

AUTHORITY: N/A.

SUMMARY: Volunteer In-Home Visitor Program: This friendly visitor program pairs VA trained and vetted volunteers with Veterans for non-clinical companionship. Veteran participants, many of whom suffer from loneliness and/or social isolation, are clinician-referred. The visits also provide caregivers regular respite (2–4 hours/week) during the visits. Volunteers are fingerprinted, background checked, given orientation, and initial and ongoing training. Volunteers often serve as an extra set of eyes and are among the first to know and report changes in the Veteran's condition and/or their environment. We are currently working to develop an evaluation tool to help measure the impact of the program.

Compassionate Contact Corps: This program was borne out of COVID-19. In March 2020, VA suspended its Volunteer In-Home Visitor Program, due to the high-risk demographics of the Veterans, caregivers, and many of our volunteers. What was created and implemented using the foundation of the in-home visitor program, was a non-clinical tele-support program. This allowed volunteers to continue filling an even more crucial need for Veterans and their caregivers, while expanding access to this service to Veterans from across VHA.



The Office of Voluntary Service is working to create a series of marketing and communication materials, as well as develop an evaluation tool to measure the impact of the program on Veterans, caregivers, and the volunteers who serve.

PROGRAM NAME: Caregiver Support Program (CSP)

TARGET CAREGIVER POPULATION(S): Caregivers participating in VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC) or the Program of General Caregiver Support Services (PGCSS)

URL(s): <https://www.caregiver.va.gov/>

National Caregiver Support Line: 855.260.3274.

[Caregiver Support Program Staff](#) (State Directory).

[Peer Support Mentoring:](#) Peer based learning network contributing to skill building and peer-based support and guidance.

[Spanish-Speaking Telephone Support Groups:](#) Caregivers participating in VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC) or the Program of General Caregiver Support Services (PGCSS)

[Publications and Resources by Topic](#) (listed by Diagnosis, concern, or topic)

Train the Trainer Caregiver Self-Care Classes.

[Building Better Caregivers:](#) Facilitated, self-paced, six-week self-care course for caregivers.

[REACH VA:](#) Resources for Enhancing All Caregivers Health. Education, Skill Building and Support for caregivers of Veterans with ALS, Dementia, MS, PTSD, or Spinal Cord Injury. Emphasis on Rural Caregivers.

[Elizabeth Dole Foundation, the Campaign for Inclusive Care:](#) In partnership with VA's Caregiver Support Program, trains providers about Veteran caregivers, the role of caregivers, impact on caregiving and how to include caregivers in the care team. The goal is to improve outcomes for Veterans, their caregivers, and their health care providers.

[AmeriCorps:](#) Volunteer based, non-institutional care effort to enable older Veterans and their caregivers to receive homemaker and other living supports and respite in their home.

[Veteran Services Organizations:](#) Chartered organizations recognized by the Secretary of Veterans Affairs work to support Veterans and caregivers.

[Rosalynn Carter Institute for Caregiving:](#) The institute's overall goal is to support caregivers through advocacy, research, and service. In partnership with VA's Caregiver Support Program, it implements [The Operation Family Caregiver Program](#) at some VA medical centers. This free program, available to those caring for a family member or friend who has a visible and/or invisible injury due to military service, provides certified coaches to problem solve issues related to caregiving.

VHA Office of Mental Health: [Suicide Prevention Toolkit for Caregivers](#)

Geriatrics and Extended Care: [Home and Community-Based Services](#) Adult Day Health Care, Home Based Primary Care, Home Hospice, Home Telehealth, Remote Monitoring, Respite, Skilled Home Care.

[Office of Connected Care:](#) "Annie App" Caregiver Self Care and Stress Management via Text Messaging: <https://mobile.va.gov/app/annie-app-veterans>

[Office of Rural Health:](#) Promising practices, educational videos, and other resources.



[Office of Mental Health and Suicide Prevention](#)

[Social Work Fisher House](#)

[Resources and Education for Stroke Caregivers' Understanding and Empowerment \(RESCUE\)](#)

[Veterans and Community Partnerships](#)

[Veterans Transportation Programs](#)

[National Resource Directory](#)

AUTHORITY: P.L. 111–163 – Caregivers and Veterans Omnibus Health Services Act of 2010; P.L. 115–182, VA Maintaining Internal Systems and Strengthening Integrated Outside Networks (VA MISSION Act).

SUMMARY: The Department of Veterans Affairs established a Program of Comprehensive Assistance for Family Caregivers (PCAFC) and a Program of General Caregiver Support Services (PGCSS), collectively referred to as the Caregiver Support Program (CSP). The CSP implemented a national caregiver staffing infrastructure and develops, implements, and supports critical programming, tools, and services. The CSP works alongside external partners and other VA program offices to contribute to a larger system of services intended to improve both Veteran and caregiver health, safety, and well-being.

In 2010, *P.L. 111–163 – Caregivers and Veterans Omnibus Health Services Act of 2010* expanded upon existing VA caregiver services and supports available through the Program of General Caregiver Support Services (PGCSS) (without application) for enrolled Veterans and their caregivers. The legislation also supported the development of the Program of Comprehensive Assistance for Family Caregivers (PCAFC) with services and supports intended to help caregivers address the needs of the eligible Veterans and Service members who were seriously injured in the line of duty on or after September 11, 2001.

On June 6, 2018, *Pub L. 115–182, VA Maintaining Internal Systems and Strengthening Integrated Outside Networks (VA MISSION Act)* was signed into law expanding the Program of Comprehensive Assistance for Family Caregivers to include eligible Veterans of all eras, in a phased approach. The MISSION Act authorizes additional services and supports and revises terms and eligibility requirements for the CSP for eligible Veterans. The MISSION Act provides Veterans greater access to health care in VA medical facilities and the community, and expands support for caregivers of eligible Veterans.

PROGRAM NAME: Veterans Experience Office - Veterans Signals (V-Signals)

TARGET CAREGIVER POPULATION(S): Family Caregivers (Note: The target population consists of Veterans that had one of the following interactions with VHA Outpatient services within the prior week: (1) scheduling an appointment, (2) visiting a health care provider, (3) labs/imaging services, (4) pharmacy services received by mail or (5) pharmacy services received in-person. These interactions make up the five survey types).

URL(s): Only approved/authorized VHA staff can access this data.

AUTHORITY: N/A.

SUMMARY: VSignals surveys such as Outpatient Services surveys and the Board of Veterans Appeals Surveys contain a “free text capability” that allows for Veterans to provide compliments, concerns, or recommendations related to their own experience with VA products and services, including their sentiment and perspective on opportunities, successes, and challenges associated with Veteran Caregivers. Using artificial intelligence that applies keyword searches to our Medallia-based Vsignals platform, insights can be extracted that specifically reference caregivers or words associated with the caregiver experience.



PROGRAM NAME: Office of Patient Centered Care & Cultural Transformation (PCCCT)

TARGET CAREGIVER POPULATION(S): Family Caregivers (i.e., Virtual seminars target caregivers, Veterans, families, and the public).

URL(s): <https://www.va.gov/WHOLEHEALTH>
<https://www.blogs.va.gov/VAntage/tag/livewholehealth/>

AUTHORITY: In accordance with the requirements of section 933 of the Comprehensive Addiction and Recovery Act (CARA), a VA pilot program on the integration of Complementary and Integrative Health (CIH) and Well-Being Programs launched the Whole Health System in 18 Flagship Facilities in FY18. No appropriations specific to caregivers.

SUMMARY: OPCC&CT staff provides consultation at VA facilities. The Portland VAMC Care Giver Support (CGS) program has embraced the integration of Whole Health in many aspects of their program, including: Use of Complementary & Integrative Health (CIH) services; integration of the Personal Health Inventory and Personal Health Plan process; new employee onboarding recommendations that include Whole Health; staff participation in Whole Health education; contributions to a video collaboration with the Elizabeth Dole Foundation and Portland with a goal to bring the caregiver into the care team; and additional consultation regarding resources and program alignment to support caregivers.

The Office of Patient Centered Care & Cultural Transformation was established by VHA in 2011 to radically redesign health care to create a health system, rather than a disease care system, that partners with the Veteran throughout his or her life.

Whole Health is an approach to health care that empowers and equips Veterans to take charge of their health and well-being, and to live their life to the fullest. The Whole Health delivery system includes three components:

Empower: The Pathway: In partnership with peers, Veterans explore their mission, aspiration, and purpose, and begin their overarching personal health plan.

Equip: Self-care through Well-being Programs: With a focus on self-care, skill building, and support, these programs are not diagnosis or disease based but support the personal health plan of each individual. Services include proactive, complementary, and integrative health (CIH) approaches such as stress reduction, yoga, tai chi, mindfulness, nutrition, acupuncture, and health coaching.

Treat: Whole Health Clinical Care: In the VA, community, or both, clinicians are trained in Whole Health and align the Veteran's clinical care with their mission and personal health plan, the foundation of which is the Veteran's self-care.

VHA Office of Geriatrics & Extended Care

PROGRAM NAME: Geriatric and Extended Care (GEC) Purchased Long-Term Services and Supports

TARGET CAREGIVER POPULATION(S): Family Caregivers (i.e., Veterans enrolled in VA for health care and are eligible for VA's Community Care Programs. Veterans who are dependent in 3 or more activities of daily living or have cognitive impairments).

URL(s): <https://www.va.gov/geriatrics/>
https://www.va.gov/GERIATRICS/Long_Term_Services_and_Supports_Overview.asp

AUTHORITY: 38 U.S.C. 1720, 1720B, 1720C. (Personal Care Services includes Homemaker/Home Health Aide and Respite Care (1993), Veteran Directed Care (2009), and Community Adult Day Health Care (1989)).



SUMMARY: Caregivers are the backbone of all VA long-term services and supports. VA coordinates its efforts in providing long-term services and supports to Veterans with CMS, and the ACL on an ongoing basis.

Office of Connected Care

PROGRAM NAME: Office of Connected Care and Telehealth Services

TARGET CAREGIVER POPULATION(S): Family Caregivers (i.e., Eligible Veterans, Service members and their Caregivers).

URL(s): <https://telehealth.va.gov/>

AUTHORITY: No specific appropriations for caregiver support. Technologies are provided under prosthetics support.

SUMMARY: Remote Patient Monitoring - Home Telehealth (RPM-HT) is a program into which Veterans are enrolled that applies care and case management principles to coordinate care using health informatics, disease management, and technologies such as in-home and mobile monitoring, messaging and/or video technologies. The goal of Home Telehealth is to improve clinical outcomes and access to care while reducing complications, hospitalizations, and clinic or emergency room visits for Veterans in post-acute care settings, high-risk Veterans with chronic disease or Veterans at risk for placement in long-term care. Utilization data is reported each quarter to determine improvements with health. Veteran satisfaction is approximately 88%.

Disease Management Protocols (DMPs) are the sessions that Veterans complete daily (for chronic care) or weekly (Low Acuity / Low Intensity). The results are securely transmitted via the technology assigned/provided to the Veteran. There are 20 DMPs developed by subject matter experts in VHA. In addition, each of the two contracted RPM-HT vendors provide their own vendor DMPs.

Annie Caregiver Text Support: Annie is a text messaging service that promotes self-care for Veterans enrolled in VA health care, as well as for caregivers, with approximately 1900 individuals enrolled in FY20. Annie sends stress management tips via text messaging to caregivers, three times per week. Messages may be educational, motivational, or an activity to manage stress. Caregivers may pause or stop the service at any time.

My HealtheVet: VA's Personal Health Record, My HealtheVet (MHV) deployed a caregiver checkbox on the registration page in June of 2020. The program plans to implement Delegation (caregivers, family, anyone the Veteran chooses) to allow a Veteran to choose someone to act on their behalf or have access to their electronic health information in FY21/22.

VHA Office of Mental Health and Suicide Prevention

PROGRAM NAME: Suicide Prevention Program (SPP)/Partnerships

TARGET CAREGIVER POPULATION(S): Family Caregivers (i.e., The Suicide Prevention Caregiver Toolkit and PsychArmor S.A.V.E. training is available to all era Veterans, their caregivers and anyone seeking suicide prevention knowledge and training).

URL(s): https://www.mentalhealth.va.gov/suicide_prevention/docs/Office-of-Mental-Health-and-Suicide-Prevention-National-Strategy-for-Preventing-Veterans-Suicide.pdf

AUTHORITY: N/A.

SUMMARY: In March of 2020, SPP released a Suicide Prevention Toolkit for Caregivers. This toolkit is a comprehensive guide aimed at providing caregivers with the resources needed to help them care for Veterans, as well as themselves. The toolkit includes important information about suicide prevention, evidence-based mental health and substance use disorder treatments, and resources available to help Veterans recover, as well as meet their goals.



Suicide is a national issue, with rising rates of suicide in the general population. In addition, suicide rates are higher and are rising faster among Veterans than non-Veteran adults. There were 46,510 American adults who died from suicide in 2018, including 6,435 U.S. Veterans. Every death by suicide is a tragedy that affects individuals, families, and communities.

Unfortunately, no one strategy in isolation has been shown to be effective in ending suicide. We must come together to systematically address the larger societal issues fueling the increased rates of suicide in our nation, keeping at the forefront of our minds that we prevent suicide through meaningful connection, one person at a time. Suicide prevention is everyone's business. Caregivers play an important role in a Veteran's life; sometimes a lifesaving one. Whether they are a spouse of a Veteran, a family member of a Veteran, or a friend, they may be the first to recognize changes in mood and behavior, such as expressions of anger or emotional pain, or increasing use of alcohol or drugs. Caregivers have a vital role in supporting the Veteran and preventing crisis. VHA, Office of Mental Health and Suicide Prevention - Suicide Prevention Program (SPP) provides several outreach and educational materials to support caregivers and their role in preventing Veteran suicide.

The VA has continued to work actively in partnership with the White House, Congress, VHA networks, and federal and community partners to address the issue of Veteran suicide. VA is actively working to reach not only Veterans receiving VHA health services but also other Veterans in the community. A key goal for VA was the expansion of the public health approach to save lives by reaching Veterans, their loved ones, their caregivers, their communities, and the greater population. VA's public health strategy combines partnerships with communities to implement tailored, local prevention plans while also focusing on evidence based clinical strategies for intervention. The approach focuses on both what we can do now in the short term and over the long term to implement VA's National Strategy for Preventing Veteran Suicide.

VHA Office of Rural Health (ORH)

PROGRAM NAME: Office of Rural Health: Decisions about care: Bringing serious illness care conversations to Veterans and their families

TARGET CAREGIVER POPULATION(S): Family Caregivers (i.e., Caregivers of any Veterans enrolled in the Program of Comprehensive Assistance for Family Caregivers and the Program of General Caregiver Support Services).

URL(s): This program is currently in development. Once developed, potential caregivers and veterans will be approached during treatment at their VHA facility. Any toolkits developed based on this work will be available by contacting the project lead, Dr. Berry-Stoelzle.

AUTHORITY: N/A.

SUMMARY: The goal of this project is to develop a protocol for a VA telemedicine platform for advanced care discussions with rural Veterans and their families in their homes. It aims to improve access to care by facilitating serious illness care discussions for rural and remote Veterans. By allowing Veterans and their families to participate in ongoing and directed discussions about their preferences, we expect Veterans and their families to be better informed in making decisions for specific medical therapies.



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APPENDIX K: REQUIRED DATA FROM SURVEY

Required Survey Data

The total number of caregivers in NJ is 1.1 million

46% of caregivers live in northern New Jersey, 26% in central New Jersey, and 27% in southern New Jersey.

The Average age of caregivers was 56-65 (39.6% of respondents). 82.3% of respondents were between the ages of 46-75.

The average time spent per week engaged in caregiving activities is continuous (24/7).

- More than half (51.0%) of the respondents indicated that they are continuously (24 hours a day, 7 days a week) a caregiver. 17.6% of the respondents said they are caregivers on a part-time basis (16-30 hours per week) and 14.9% on a full-time basis (35-40 hours per week). Respondents were least likely to be caregivers for 15 hours per week or less (8.2%) and occasionally on an as-needed basis (6.5%).

The average total period of time spent in caregiver role was more than 5 years.

- More than half, or 53.4% of the caregivers indicated that they have provided care for more than five years. Progressively fewer respondents have provided care for less than 5 years.

81.8% of respondents indicated that caregiving interfered a little or more with their ability to maintain or start a job outside the home. 29% of respondents lost pay due to missing work to engage in caregiving activities

Caregivers report:

- 14.6 % went from working full-time to part time.
- 14.2% reported having to ask others for financial help.
- 21.8% gave up working entirely to provide care for a loved one.
- 15.6% have taken a leave of absence from your job to provide care for a loved one.
- 38.6% have gone into work early or late, or take time off to provide care for a loved one.

Nature and severity of illnesses or conditions suffered by persons being cared for (From most to least)

- Older Adult (65 years or older)
- Memory/Cognitive Impairment(dementia, Alzheimer's, TBI, MCI, stroke)
- Chronic Illness/Health Condition(s)
- Physical Disability
- Intellectual/Developmental Disability
- Sensory Disability (deafness/hearing loss, visual impairment/low vision)
- Mental Illness
- Long term impacts of COVID19

The existing support services that are most commonly used by caregivers were medical supplies and equipment (31.7%), lawn service/snow removal (31.0%), equipment therapies (Occupational, Physical, Cognitive, and Speech) (36.4%), prescription assistance (25.9%) and visiting nurse (24.8%).

APPENDIX L: CAREGIVER BRFSS INFOGRAPHIC (2018)

NEW JERSEY CAREGIVING

2018 Behavioral Risk Factor Surveillance System (BRFSS) Data

1 in 5 adults are caregivers

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

WHO ARE CAREGIVERS?

- 59% are women
- 27% are 65 years old or older
- 44% are caring for a parent or parent-in-law
- 11% of caregivers are providing care to someone with dementia

CAREGIVING CAN BE

- LENGTHY**
Nearly 60% have provided care for at least two years
- INTENSE**
Almost 1/3 have provided care for at least 20 hours per week

HOW DO CAREGIVERS HELP?

- Over 50% manage household tasks
- Nearly 50% assist with personal care

FUTURE CAREGIVERS

1 in 9 NON-CAREGIVERS expect to BECOME CAREGIVERS within 2 years

[cdc.gov/aging](https://www.cdc.gov/aging)

CS 294325-A March 2020

Footnotes

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